

An Interpretative Phenomenological Analysis of the Experiences of Fathers of Adults diagnosed with Asperger's Syndrome or High Functioning Autism.

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1. ABSTRACT

Existing research has started to explore the experiences of the people around children and adults diagnosed with Asperger's Syndrome (AS) and High Functioning Autism (HFA). However, there are very few studies looking at the experiences of fathers, and there are less studies in relation to adults rather than children. This study aims to take an in depth look at the experiences of these fathers in order to start building our knowledge of the experiences of being the father of someone with a diagnosis of AS or HFA.

Four fathers of sons and three fathers of daughters with a diagnosis of AS or HFA were interviewed using a semi-structured interview. The experiences of the fathers were explored qualitatively, using Interpretative Phenomenological Analysis. Analysis of the transcripts brought out four superordinate themes for the seven fathers. The first theme: 'The changing role but constant responsibility of being a 'Father'' described the fathers' perceptions of their roles and responsibilities towards their child as they have grown up and into the future. The second theme: 'The importance of knowledge and understanding' described the importance the fathers placed on developing their understanding of their child and the need for other people to understand them and their child. The third theme: 'The intense emotional impact' came from the fathers' descriptions of the positive and negative emotional reactions to the challenges their children and families have faced. The final theme: 'The importance of good support' includes the fathers' good and bad experiences of support services and support from family and friends.

The results of the analysis are discussed in relation to the existing literature and in terms of what they mean for the clinical practice of people working with fathers of children and adults with AS or HFA. The strengths and limitations of the study are also discussed.

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2. INTRODUCTION

2.1. Identifying Autism Spectrum Conditions

2.1.1 Diagnosis

It is estimated that more than 1 in 100 people in the UK have an Autistic Spectrum Condition (ASC), (Brugha et al., 2012). The National Autistic Society (NAS) estimates that between 44-52% of people with ASCs may also have an intellectual disability (NAS, 2015).

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) requires that a person meets five criteria to receive a diagnosis of Autism Spectrum Disorder (ASD). Firstly, criterion A states that there must be: “persistent deficits in social communication and social interaction across multiple contexts”. Secondly, criterion B states that they must display: “Restricted, repetitive patterns of behaviour, interests, or activities”. Criterion C states that symptoms must occur in early childhood and Criterion D requires that the above ‘symptoms’ must cause significant impairment in functioning. Lastly, Criterion E requires that there must not be a better explanation for these difficulties (American Psychiatric Association, 2013, p.50).

The International Statistical Classification of Diseases and Related Health Problems, Tenth Edition (ICD-10), is widely used in Europe in the diagnosis of disorders. The ICD-10 describes Pervasive Developmental Disorders, which includes the categories of child-hood autism, atypical autism and Asperger’s Syndrome (AS). Pervasive Developmental Disorders are described as being characterised by: “qualitative abnormalities in reciprocal social interactions and in patterns of communication and by restricted, stereotyped, repetitive repertoire of interests and activities” (World Health Organisation, 1994, p. 198). A diagnosis of Asperger’s syndrome may be given if the person did not have any developmental delay in language or cognitive function.

This separate category of Asperger’s Syndrome was also present in the DSM-IV, which also classified it as a Pervasive Developmental Disorder, similar to Autism, but without:

... significant delays in language (...). In addition, there are no clinically significant delays in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour (other than in social interaction), and curiosity about the environment in childhood (APA, 1994, p.75).

A person might have been given a diagnosis of High Functioning Autism (HFA) if they are of average or above average intelligence, but there was some delay of language or cognition in their early years. These categories of Asperger’s Syndrome and High Functioning Autism, which were present in DSM-IV were combined into the broader, dimensional category of Autism Spectrum Disorder in the DSM-5.

This change has been welcomed by some, who felt that there was no difference between AS and HFA. However, there have also been those who have protested the change, such as those people who have built their identity around their diagnosis of AS, for example the 'Aspie' community (Giles, 2014),

Traditionally ASCs have been understood using Wing and Gould's (1979) 'Triad of Impairments'. Wing and Gould proposed that ASC could be understood in terms of three areas of impairment:

- Social and Emotional: Difficulties with: friendships, managing unstructured parts of the day, working co-operatively.
- Language and Communication: Difficulty processing and retaining verbal information, Difficulty understanding: Jokes and sarcasm, Social use of language, Literal interpretation, Body language, facial expression and gesture.
- Flexibility of thought (Imagination): Difficulty with: Coping with changes in routine, Empathy, Generalisation.

(NAS, 2015)

The NAS (2015) also comments that in addition to impairments related to the Triad, people with ASC may have difficulties with motor-co-ordination and organisational skills. People with ASC also frequently show sensory sensitivities, which Hans Asperger commented on in his first description of 'autistic psychopathy':

In the sense of taste we find almost invariably very pronounced likes and dislikes. (...) It is no different with the sense of touch. Many children have an abnormally strong dislike of particular tactile sensations, for example, velvet, silk, cotton wool or chalk. They cannot tolerate the roughness of new shirts, or mended socks (...) There is hypersensitivity too against noise. (Asperger, 1944, translated by Frith 1991, p.80)

The prevalence of mental health difficulties is high in people with ASC (Ghaziuddin, 2005). Attwood (2007) comments on the possible causes of depression for people with AS:

...[reasons] include the long-term consequences on self-esteem of feeling unaccepted and misunderstood, the mental exhaustion from trying to succeed socially, feelings of loneliness, being tormented, teased, bullied and ridiculed by peers, and a cognitive style that is pessimistic, focusing on what could go wrong (p.141).

Attwood (2007) also writes about how anxiety for people with ASC can be related to an avoidance of situations which are difficult because of sensory sensitivities and how people's behaviour can become quite rigid and controlling in order to help manage this anxiety (p.137).

2.1.2 Is there a difference between Asperger's Syndrome and Autism?

It is widely argued as to whether there is any validity in having the separate categories of Autism and AS. Sanders (2009) argues that there is no qualitative difference between AS and Autism, but that differences may be a “function of individual variability” (p. 1560). Frith (2004) states that: “...the behavioural and neuro-physiological evidence to date suggests that Asperger syndrome is a variant of autism typically occurring in high functioning individuals, and not a separate disorder” (p. 672).

Lord et al. (2012) carried out a large, multi-site study looking at how clinicians diagnosed different ASCs (Autistic Disorder, Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS) or AS). They found that, though all clinicians were using standardised diagnostic, cognitive and behavioural measures, there was variation in where clinicians placed a ‘cut- off’ for different diagnoses (e.g. IQ scores for differentiating between Autism or PDD-NOS and AS ranged from 62-127) and differences in the weight they placed on different parts of the diagnostic process in coming to a conclusion, leading to unreliable clinical distinctions. Lord et al. (2012) conclude that: “Results support the move from existing subgroupings of autism spectrum disorders to dimensional descriptions of core features of social affect and fixated, repetitive behaviours, together with characteristics such as language level and cognitive function” (p. 306).

2.1.3 Is there an ASC epidemic?

Alan Zarembo, of the Los Angeles Times, comments that “Autism rates have increased twentyfold in a generation” (Zarembo, 2011). Some people argue that this is due to environmental changes, which are causing more cases of ASC in children. Zarembo reports that there is some research supporting the theory that exposure to rubella and some drugs during pregnancy can lead to ASC, but exposure to these does not explain the majority of ASC cases. The idea that childhood vaccinations trigger ASC has also been widely debated, and though Wakefield’s (1998) research paper stating a link between the combined Measles, Mumps and Rubella (MMR) was fully withdrawn by The Lancet in 2010, and multiple studies have found no link, there remain large groups who maintain that vaccinations and ASC are linked (e.g. www.ageofautism.com).

Other explanations of the increase in ASC rates point to changes in diagnostic procedure and support policies. The recent changes from DSM-IV to DSM-V show how diagnoses can change according to ongoing research and the political landscape. Veague (2009) comments on how each DSM edition from 1980 to 1984 broadened the diagnostic criteria for autism, meaning that with each revision more children would be diagnosed. In addition increased awareness of ASC amongst families and health and education professionals leads to more referrals for assessment.

The diagnosis of ASC can gain extra support for children with ASC and their families, through extra support at school and care at home. Veague (2009) comments: "the availability of special advantages in any form can motivate parents and educators to diagnose a child with a condition simply to obtain access to the Individual Education Plan (IEP)" (p. 88). Whilst this may be the case for some children, it is also likely that the increased availability of support has led to increased diagnoses for families who may not have seen the utility in labelling their child with ASC in the past.

2.1.4 Different presentations of AS and HFA in males and females

Attwood (2007) describes some of the differences between males and females with ASC that he has observed in several years of diagnostic assessments. Attwood (2007) comments that girls frequently are not identified as having difficulty with social relationships as they are more likely to develop coping mechanisms, such as observing and copying social rules and may form strong friendships with a single 'mentor'.

Attwood (2007) suggests that the language and cognitive profile for boys and girls with AS may be quite similar, but a girl's special interests may not appear as "idiosyncratic or eccentric" as those that some boys with AS may have. Attwood is quoted in a newspaper article commenting on the difficulties of diagnosis of girls with ASC:

Boys tend to externalise their problems, while girls learn that, if they're good, their differences will not be noticed," he said. "Boys go into attack mode when frustrated, while girls suffer in silence and become passive-aggressive. Girls learn to appease and apologise". (Hill, 2009)

2.2 Psychological Theories of ASC

2.2.1 Theory of mind

In a 1985 paper Baron-Cohen, Leslie and Frith proposed that children with ASC lack a 'theory of mind'. Attwood (2007) wrote of theory of mind as: "the ability to recognize and understand thoughts, beliefs, desires and intentions of other people in order to make sense of their behaviour and predict what they are going to do next" (p.112). This ability is also sometimes called 'mentalizing'. The idea that people with ASC do not have a theory of mind helps to explain the difficulties that people with ASC have in social interactions, as they may find it difficult to understand the thoughts and intentions of the person they are interacting with and may not recognise that the other person does not share the same knowledge that they do.

There are several tests that have been used to test the theory of mind of people with ASC, such as the Sally-Anne test of false belief (Baron-Cohen, Leslie and Frith, 1985) and the Pencil in a Smarties box

(Perner, Frith, Leslie and Leekam, 1989). These tasks require the person to understand that they have knowledge that another person could not have and predict what another person would do. Happé (1995) found that the majority of neuro-typical children can pass a test of false belief by the age of five and the majority of children with a learning disability can pass by the mental age of five. However, children with ASC did not pass the tasks of false belief until a mental age of around ten years and many could not pass even then. Frith (2003) suggests that the result that some people with ASC developed the ability to pass tests of false belief shows that: "Intuitive mentalizing ability may not be necessary. One can learn about mental states through explicit rules of logic" (p.94). Some people with ASC can learn compensatory behaviours, which may make it appear that they can consider another person's mental state, but: "knowledge about mental states that results from compensatory learning remains fragile and results in frequent mistakes" (Frith, 2003, p.94).

2.2.2 Weak central coherence

Frith and Happé (1994) discuss experimental and anecdotal findings that the theory of mind model cannot explain, such as the restricted repertoire of interests, a desire for sameness and preoccupation with parts of objects (p.119). Frith (1989, 2003) proposed a model based on central coherence. Central coherence can be described as the intuitive ability to bring bits of information together to make sense of the whole picture, for example, the context of a word such as 'tear' in a sentence helps people to determine how to pronounce it and the meaning to attribute to it (Happé, 1997, in Baron-Cohen, 2000, p.496). Frith (1989, 2003) suggested that people with ASC have a weak central coherence, in other words they do not tend to combine the separate details into the whole picture, but instead they may view each detail in isolation. This idea was backed-up with tasks such as the Children's Embedded Figures Test (Witkin et al., 1971, cited in Frith, 2003), which Shah and Frith (1983) used with children with ASC. They found that children with ASC were faster and more accurate in finding the target shape within a larger, meaningful drawing than was the average for their mental age, suggesting less interference from the whole drawing and more focus on the details.

2.3 Genetic and Biological explanations of ASC

There is believed to be a complex pattern of genetic mutations that may be responsible for people developing with ASC. There appears to be a link between whatever causes ASC and gender, as a much larger proportion of people with ASC are male rather than female. Zhao et al. (2007) suggest that high risk families have a 50% possibility of male offspring with ASC due to transmission of a causative mutation, whilst in low risk families ASC occurs due to a sporadic mutation (p.12831). Attwood (2007) explores the research around genetic inheritance of ASC, and concludes: "There is something in the genes" (p.328). However, it is thought that it is likely that there are multiple genes responsible,

interacting with each other and with the environment (NAS, 2015). Happé, Ronald and Plomin (2006) argue that there is evidence that social impairment, communication difficulties and rigid and repetitive behaviours could each be explained by “largely non-overlapping genes acting on each of these traits”.

There have been some studies of the ‘cognitive phenotype’ of ASC or ‘broader autism phenotype’ in relatives of people with ASC. Happé, Briskman and Frith (2001) found that fathers of boys with autism also showed weak central coherence across four tests of central coherence. Baron-Cohen et al. (1998) suggest that there were significantly more incidences of ASC in the families of students who were studying Physics, Engineering and Mathematics than in the families of students studying Literature. They suggest that Physics, Engineering and Mathematics are occupations where a person with the cognitive phenotype observed in ASC would do well. Baron-Cohen et al. (1997) also found that fathers and grandfathers of children with autism were more likely to work in the field of engineering.

Eisenberg (1956) described the characteristics of fathers of 100 children with ‘infantile autism’. He described 85 out of 100 of the fathers as being; “obsessive, detached and humourless individuals... Though intellectually facile, they are not original thinkers. Perfectionistic to an extreme” (p. 721). To place this within the prevalent thoughts on autism of the time, Eisenberg was attempting to extend the cause of autism away from being purely the parenting of the mother, to include the parenting style of the father. Within the current theories on ASC we might surmise that perhaps the fathers in Eisenberg’s study may have displayed traits of ASC themselves.

Given the likely genetic link present in ASC, it is possible that some of the fathers interviewed in this study will have AS or HFA themselves. Therefore, consideration of the underlying characteristics of ASC will be important to bear in mind during the interview process, for example, in using concrete language, in directing the interview if a participant is talking about a special interest in depth and in asking specific questions where a participant assumes knowledge.

2.4 ASC: Difference, disorder or disability?

2.4.1 Difference or disorder?

The idea that ASC is a difference rather than a disorder started to be discussed by Frith (1989) and has been developed in relation to thinking about weak central coherence as a ‘cognitive style’ rather than a ‘cognitive deficit’ (Happé, 1999). This cognitive style is used to explain not only the difficulties but also the strengths and islets of ability that are frequently seen in people with ASC. Happé (1999) writes about a normal distribution of central coherence (CC):

Because weak CC provides both advantages and disadvantages, it is possible to think of this (...) as akin to a cognitive style – a style that might vary in the normal population. There might perhaps be a normal

distribution of cognitive style from 'weak' CC (preferential processing of parts – for example, good proof reading), to 'strong' (preferential processing of wholes – for example, good gist memory) (p.220).

This idea suggests that people with ASC tend to sit further towards the 'weak' end of a central coherence spectrum. This spectrum has also been thought of as a line between local and global information processing styles (Happé, 1999). It also links to Baron-Cohen's (2002) idea of 'systemizing', "which is based on an intuitive understanding of how mechanical things work and a preference for information about the physical as opposed to the psychological world" (Frith, 2003, p.163). Kanner (1943) mentioned a similar observation in his writings on autism: "our children are able to establish and maintain an excellent, purposeful, and 'intelligent' relation to objects that do not threaten to interfere with their aloneness, but are from the start anxiously and tensely impervious to people" (Kanner, 1943, p.249).

If we think of these cognitive styles on a spectrum, we can see that there are advantages of having a more local processing style, or understanding how mechanical things work for certain hobbies and occupations. When writing in 1944 Hans Asperger also recognised the strengths of the people he was describing: "In some cases, however, the problems are compensated by a high level of original thought and experience. This can often lead to exceptional achievements in later life" (translated in Frith, 1991, p.37).

2.4.2 Disability?

There is some debate as to whether people with AS or HFA should be seen as having a disability. Baron-Cohen (2000) lays out several arguments for and against labelling AS or HFA as a disability. The label of disability gives people with AS or HFA access to support and reasonable adjustments as they are protected from discrimination under the Equality Act (2010). The Act states: "A disability can arise from a wide range of impairments which can be: (...) developmental, such as autistic spectrum disorders (ASD), dyslexia and dyspraxia" (Office for Disability Issues, 2010, p.9). Under the Act, a person has a disability if the impairment: "has a substantial and long term adverse effect on his or her ability to carry out normal day-to-day activities" (Office for Disability Issues, 2010, p.5). Baron-Cohen (2000) comments on the utility of the 'disability' label:

Such individuals clearly have special needs (...) and access to such support in the present legal framework only flows to the child and their family if the case can be made that autism is a disability. Special funding does not automatically flow simply because one regards the child as "different" (p.494).

Norbury and Sparks (2013) ask:

Should psychologists persist with a very Western medical model of disability, in which the problems faced by individuals are part and parcel of their disease, or should a more social model of disability be adopted, which focuses on society's ability to adapt to the variable language and communication needs of the population as a whole? (p.46).

If this adaptation from society as a whole became the norm, then people with ASC would cease to be considered disabled. Baron-Cohen (2000) also speaks of a social view of disability in relation to ASC: "Being more object focused than people focused is clearly only a disability in an environment that expects everyone to be social (...). On this view, people with AS/HFA would cease to be disabled as soon as society's expectations change" (p.491).

2.5 Choice of Language for this study

The children of the fathers in this study are likely to have received their diagnosis prior to the introduction of the DSM-V and so would be more likely to have received the diagnostic label of Asperger's Syndrome or High Functioning Autism. This will be the name that they and the family are accustomed to using and these terms are still widely used in services that support people on the Autistic spectrum. Therefore Asperger's Syndrome (AS) and High Functioning Autism (HFA) will be used throughout this study. I consider these terms to reflect a situation where a person displays the traits of ASC and does not have an intellectual disability. In referring to the general spectrum of difficulties I will use the term 'Autism Spectrum Condition' (ASC) rather than 'Autism Spectrum Disorder' (ASD). I find the word 'condition' preferable to 'disorder', as disorder implies: "something might be broken in their mind or their brain" (Baron-Cohen, 2012), whilst 'condition' is a more neutral description of a state of being.

3. LITERATURE REVIEW

The area of ASC is widely researched from many perspectives, from the study of the genetics of ASC to the experiences of people with an ASC diagnosis and their families. For the purposes of this study I am more focused on the experiences of the people around those who have an ASC diagnosis, particularly the fathers. As there are limited studies around the experience of fathers of adults with AS or HFA I will also examine research in relation to mothers and parents, as Flippin and Crais (2011) comment: “Even in today’s world of increased co-parenting by fathers, participants in ‘parent’ studies in ASD are almost exclusively mothers” (p.44). In this section I will present some of the relevant literature from both a quantitative and qualitative viewpoint. I will end by stating my research question.

3.1 Quantitative research with parents and families

3.1.1 Experience of the diagnosis and adjustment

Milshtein, Yirmiya, Oppenheim, Koren-Karie and Levi (2010) examined the characteristics of the child and parent that lead to acceptance and resolution post-diagnosis with parents of sixty-one children with ASC, aged two to seventeen years. They describe acceptance and resolution as the point when pre-diagnosis internal representations: “are worked through and integrated with the post diagnostic internal representations of the self and the child” (p.89). 50% of the fathers who participated were rated as being ‘resolved’ to the diagnosis, as were 36% of their partners. Mothers, but not fathers, were more likely to report negative impact on their relationships if they were unresolved. The authors hypothesise that the fathers were more likely to underplay the negative impact than the mothers.

3.1.2 Stress and parenting a child with ASC

A large amount of research has examined parenting stress in parents of children with ASC, in comparison to parents of children with other diagnoses, or ‘neuro-typical’ children. The research has examined the causes of stress, whether the causes are located within aspects of the child or aspects of the parent and compared the levels of stress across different diagnoses and parent gender.

Noh, Dumas, Wolf and Fisman, (1989) compared stress levels in parents of children with ASC (n=31) to parents of children with conduct disorder (n=35), Down’s syndrome (n=31) and children with ‘normal’ development (n=62). Using multiple regression analyses of their scores on the Parenting Stress Index they found that parents of children with conduct disorder or with ASC experienced higher stress. They discuss how this is related to child characteristics related to acceptability, adaptability and demandingness. Keller and Honig (2004), in a study of parents of children with disabilities (thirty

parent pairs), found that children's demandingness and neediness for care were related to maternal stress and that stress for fathers was more about the child's acceptability. Bundy and Kunc (2009), in a mixed methods study of twenty-four parents (83% of sample were mothers), found that parents were reporting seven sources of stress: Parent personal/ emotional difficulties, School-related difficulties, Motor skills, Specific behaviour difficulties, Difficulties with siblings, Social skills and Concerns about child's future.

Using an anonymous survey (n=219) Sharpley, Bitsika and Efremidis (1997) found that the parents of children with ASC showed elevated levels of stress, with the most common cause being reported as the behavioural problems of their child. Mothers reported higher stress than fathers, but also reported higher levels of confidence in their own ability to look after their child. Tehee, Honan and Hevey (2009) reported that mothers of children with ASC score higher than fathers on measures of general stress, caregiving stress, coping and involvement. Dabrowska and Pisula (2010) also found that parents of preschool children with ASC reported higher levels of stress than parents of children with Down's syndrome. Mothers reported higher levels of stress than fathers in the ASC group.

Epstein, Saltzman-Benaiah, O'Hare, Goll and Tuck (2008) found a positive correlation between mothers' parenting stress and their child with AS's level of impairment in regards to executive dysfunction and sensory sensitivities. Mori, Ujiie, Smith and Howlin, (2009), also found higher levels of stress in parents of children with Autism or AS in comparison to parents of neuro-typical children, in Japan. In addition they found that parents of children with AS reported higher stress than the parents of children with autism. The authors surmise that this higher stress is due to behaviour of the child and perceptions of the parent. These results should be treated with caution in relation to parents in the UK, as it is possible that cultural differences between the UK and Japan would result in different parental perceptions and also different ideas about the behaviour of children.

In America, Rao and Beidel (2009) looked into the stress experienced by parents of children with HFA, compared to parents of children with 'no psychological disorder'. They found that parents of children with HFA; "experience significantly more parenting stress, and that the higher intellectual functioning in children with HFA does not compensate for the stress associated with parenting children with autism spectrum disorders" (p. 437). The higher levels of stress are attributed to child characteristics, such as behaviour. Falk (2012) proposes that parental cognitions and socio-economic support mediates the relationship between "child-centric variables" and parental distress (p.7).

Davis and Carter (2008) looked at parenting stress in parents of fifty-four toddlers with ASC, comparing results on standardised interview and questionnaire measures. Parents reported elevated levels of stress and the children's social-relatedness was associated with overall parenting stress for both

parents. Mothers' stress was associated with regulatory problems in their children, whereas fathers' stress was associated with externalising behaviours.

Fayerberg (2012) compared stress and wellbeing for fathers of children with ASC (n=38) to fathers of typically developing children (n=60). Fayerberg (2012) found that fathers of children with ASC reported significantly higher levels of stress and significantly lower levels of subjective wellbeing. She also found that there was no evidence for three other hypotheses: fathers of children with ASC did not report significantly higher levels of depression or anxiety or higher levels of secondary trauma than fathers of children without ASC.

Blair, Block, Chambliss, Hobbs and Urgarte (1996) undertook a survey with parents of children with ASC. 31% of parents reported an adverse impact of stress on their marriage, whilst 34% reported that their marriage was stronger because of the stresses. Phelps, McCammon, Wuensch and Golden (2009) found that parents reported high levels of stress related to their relationship with their partner. They also suggest that "caregivers who are enriched in their emotional health, friendships, orderliness and view of self, often have lower stress" (p. 138).

3.1.3 Wellbeing and Quality of Life

Several studies have examined wellbeing in mothers of children with ASC. Abbeduto et al. (2004) compared maternal wellbeing between mothers of children with Down syndrome (n=39), Fragile X syndrome (n=22) and ASC (n=174). Mothers of children with ASC reported significantly more depressive symptoms, with more in the clinical range for depression. They also reported higher levels of pessimism and more distant relationships with their child. Hartley, Seltzer, Head and Abbeduto (2012) examined depressive symptoms, pessimism and coping in fathers of adolescents and young adults with ASC (n=135), compared to fathers of young people with Down syndrome (n=59) and Fragile X syndrome (n=46). They found that fathers of people with ASC reported a higher level of depressive symptoms than fathers of people with Down syndrome or Fragile X and a higher level of pessimism than fathers of people with Down syndrome.

Lounds, Seltzer, Greenberg and Shattuck (2007) examined maternal wellbeing in relation to transitions for their child with ASC. They found that maternal wellbeing improves when sons and daughters reach adolescence and early adulthood, though many of the mothers were at elevated risk of psychological distress compared to national norms, as measured by higher levels of symptoms of depression and anxiety. Ogston, Mackintosh and Myers, (2011) found that mothers of children with ASC reported greater future related worry than mothers of children with Down syndrome and that mothers of children with ASC reported lower hope. Barker et al. (2011) examined trajectories of wellbeing of

mothers of adolescents and adults with ASC over a ten year period. Wellbeing was again measured using symptoms of anxiety and depression. They found that wellbeing was lower when behaviour problems were higher, when social support networks were smaller and when stressful life events occurred. Wellbeing was higher when grown children moved out of the family home.

Laxman et al. (2014) found that fathers' responsive caregiving and fathers' literacy when a child with ASC was nine months were associated with lower maternal depression at four years old. This relationship was not found for fathers and mothers of typically developing children or children with other disabilities. Laxman et al. (2014) suggest that this may be linked to fathers' responsiveness to the self-regulation difficulties and communication difficulties that can often occur in children with ASC.

Magana and Smith (2006) compared Latina and non-Latina White mothers of children with ASC in America. Latina mothers showed significantly less anger and fatigue, significantly more environmental mastery and better overall psychological well-being. Despite Latina mothers being younger, having a lower income, being less likely to be married or employed and being in poorer health, being non-Latina White was "predictive of greater psychological distress and lower psychological well-being" (p. 351). Higher maladaptive behaviours in the children of non-Latina White mothers partially explained this relationship between wellbeing and ethnicity. Latina mothers reported higher satisfaction with their son or daughter living at home. The authors propose that satisfaction with co-residence mediates all of the outcomes except anger and fatigue.

Allik, Larsson and Smedje (2006) examined the health related quality of life of parents of children with AS or HFA. Thirty-one mothers and thirty fathers of children with AS/HFA completed measures of their health and wellbeing, which were compared to similar numbers of parents of children with typical development. They found that mothers but not fathers of the children with ASC reported lower health-related quality of life, indicating poorer physical health. They also found a relationship between the mothers' well-being and difficult characteristics of the child's behaviour. This study was carried out with parents in Sweden, so may not be transferable to the UK. Dardas and Ahmad (2014), in their larger Jordanian study (fathers= 70, mothers= 114), also found that difficult child characteristics predicted maternal quality of life, alongside house-hold income and number of siblings. Parental distress predicted lower quality of life for both mothers and fathers. However, again, this may not be transferrable to the UK. In America Lee et al. (2009) compared physical and mental health related quality of life of eighty-nine parents of children with HFA to the quality of life of forty-six parents of children without disabilities. They found that both physical and mental health aspects of quality of life

were lower for parents of children with HFA and parents of children with HFA reported: “significantly higher levels of stress and significantly lower levels of adaptive coping and resources” (p.234).

3.1.4 Coping

Interlinked with the idea of stress and well-being, is the idea of coping with that stress and the challenges of parenting a child who is ‘different’. Pottie and Ingram (2008) measured mood in ninety-three parents of children with ASC compared with the coping strategies that they use. Higher levels of positive mood were predicted by: problem focused coping, social support, positive reframing, emotional regulation and compromise coping. Decreases in daily positive mood were linked with: escape, blaming, withdrawal and helplessness coping. Lower levels of daily negative mood were predicted by: distraction and emotional regulation coping. Higher levels of daily negative mood were associated with increased use of: problem-focused, blaming, worrying and withdrawal coping. They did not find any different effects for gender. They comment that as problem-focused coping predicts both high positive and high negative mood, it may not be an adaptive way of coping for some. The authors highlight the advantages of collecting data at different points in time, without relying on retrospective accounts.

Sivberg (2002) compared strain and coping behaviours between parents of children with ASC (thirty-seven families, sixty-six parents) and parents of neuro-typical children. Sivberg (2002) found that the level of strain on the family system was greater in the families with a child with ASC. They also found that parents of children with ASC scored higher on the coping behaviours of distancing and escape. Sivberg (2002) reported that their results suggest that parents of children with ASC develop avoidant coping behaviours in response to the ASC, in contrast to the antiquated view of ‘refrigerator’ parents, who cause ASC through their distant parenting style. However, parents with avoidant coping styles may be less likely to use strategies which can reduce the challenging behaviours of ASC, such as those suggested in the SPELL framework (Structure, Positive approaches and expectations, Empathy, Low arousal and Links) used by National Autistic Society (NAS) services. The overall strain on the family system may lead to increased ASC symptomatology as the child reacts to the family environment. Therefore, there may some mutual maintenance of the need for avoidant coping for the parents due to the strain of coping with the challenging aspects of ASC, and an increase of challenging behaviour in response to the avoidant coping. Sivberg (2002) also reported low scores on social support for parents of children with ASC, reflecting “their social networks having deteriorated over the years owing to the overall strain on the family system” (p.407).

3.2 Qualitative research with parents and families

3.2.1 Qualitative research with Parents

Ryan and Salisbury (2012) thematically analysed the experiences of twenty-four parents (eighteen mothers) prior to the diagnosis of autism. They identified that parents fell into three groups: those having no concerns prior to diagnosis, those having concerns but who had not sought any further information and those who had concerns and had been actively seeking explanation. Those who had not been concerned reported difficult experiences in being informed by others that they should seek an expert opinion and difficulties in adjusting their view of their child. Those in the passively concerned group described their concern increasing over time and difficulties in articulating their concerns. Those in the actively concerned group fell into two groups, those whose concerns were rapidly acted on and those who were reassured and took some time to get a diagnosis. This study helped to shed some light on the experiences of parents pre-diagnosis, but lacks some clarity in the numbers of parents who fell into each group and provides little information on actual experiences of these parents, outside of classifying them into the three groups.

Altiere and Von Kluge (2009) interviewed twenty-six parent couples of children with ASC about their child. Using a Grounded Theory approach they found that they could categorise parents' experiences into five different challenges: 'Development, Questioning, Devastation, Solutions and Growth'. Altieri and Von Kluge (2009) report how all of the parents described feeling devastated when they discovered their child had ASC, but that parents: "were swift and eager to mobilise resources to help their child, sometimes in any possible way" (p.142). They also described the positive experiences parents reported, despite the challenges.

York (2007) interviewed the parents of eight children with AS (Eight mothers and five fathers). Using constant comparison, a method informed by Grounded Theory, York identified a core concept of a "balancing act". Within this core concept York (2007) had three key themes, which occurred at different times. "Losing our footing" occurred as parents realised that there was something different about their child and in the process of getting a diagnosis. "Regaining our balance" occurs as parents receive the diagnosis and learn new information about AS and parenting. As parents regained their balance they were able to start "Helping others find their balance". Interestingly Robinson, York, Rothenberg and Bissell (2014) used the same research and reported just the two themes of 'losing our footing' and 'regaining our balance'.

Lasser and Corley (2008) interviewed twenty parents of children with AS (nineteen mothers, one father). Using Grounded Theory they found the core concept of "constructing normalcy". Parents reported that they tried to understand their experiences through understanding 'normal' in relation to themselves and their children. Parents found this was complicated by the hidden nature of AS, as

their children would appear 'normal' to other people most of the time. Parents also reported that they tried to construct a 'normal' life for their children through social and leisure experiences. Lasser and Corley (2008) do not comment on the fact that the large majority of their parent sample were mothers and they do not consider the impact of gender on their results.

Woodgate, Ateah and Secco (2008) used a hermeneutic phenomenological approach to describe the experiences of twenty-one parents of children with ASC (sixteen mothers, five fathers). Woodgate et al. (2008) reported that the essence of the parents' experiences was "Living in a World of Our Own". Three themes emerged: vigilant parenting, sustaining the self and family and fighting all the way, which described the challenges for the parents. Hoogsteen and Woodgate (2013) also used a hermeneutic phenomenological approach to explore the experiences of parents of children with ASC who lived in rural areas in Canada. Interviews with twenty-six parents (twenty-two with mothers, two with both parents and two with fathers) produced an overall theme of making 'the invisible, visible'. Major themes within this included: "he's not the Rain man", "society's lack of knowledge and understanding" and "doing it on our own".

Myers, Mackintosh and Goin-Kochel (2009) used content analysis on answers to the question: "How has your child on the autism spectrum affected your life and your family's life?". Parents (92.2% mother) completed their answers via an online questionnaire (n=493). They found five clusters of themes: "Stress", "Child's behaviour", "Parents' personal well-being, work and marital relationship", "Impact on the whole family" and "Social isolation". They found fifteen negative and nine positive themes which they sorted into these clusters and concluded that parents can find the positive meaning of life, whilst dealing with the negative aspects of parenting a child with ASC.

Griffith, Totsika, Nash, Jones and Hastings (2012) spoke to the parents (three mothers and one couple) of middle-aged children with AS about their parenting experience. Their Interpretative Phenomenological Analysis of their interviews brought out six superordinate themes. The first theme, "We are all there silently coping", spoke of the parents' experiences of being the primary source of practical and emotional support for their sons, which was seen as a natural part of the parent role. "He doesn't look disabled", described the need parents felt to advocate with services to ensure support for their sons. Parents worried about their sons' social isolation, though this was framed in terms of their own worry, rather than the impact this had on their sons. Parents described relationships with their sons that were affected by some of the common characteristics of AS. Parents expressed surprise when they were asked about seeking support for themselves, despite feeling they were being left to cope with their sons. Parents expressed worry about the future for their sons.

Golden (2012) interviewed twenty-four mothers, nine fathers and one grandmother of children and young adults with ASC, to explore relationships between care-givers and children with ASC. Using interpretative phenomenological methods Golden (2012) found that five themes emerged from the data:

- Bonding: Parent perceptions of early bonding and attachment ranged from 'highly unusual' to 'unremarkable and normal'.
- Reciprocity: An overwhelming majority of parents described their relationships as non-reciprocal.
- Barriers: A large majority of parents identified significant barriers to creating relationships with their children.
- Connections: Parent strategies for creating connections with their children ranged from "very limited" to 'well established'.
- Change: An overwhelming majority of parents described their relationships as 'growing and changing' over time, but with awareness they would remain in a caretaker role with their children. (p.59-60).

O'Neill (2013) completed a narrative exploration of the stories of parents of adults with AS or HFA. Though 'parents' were invited to participate, the sample consisted of six mothers and a couple. O'Neill (2013) identified three main 'plots' in the narratives; "Losing, questioning and ultimately attempting to strengthen one's sense of self", "The Making, Breaking, yet Ongoing and Painstaking relationships with Services" and "Nurturing a past, present and future relationship with my son". O'Neill (2013) identifies the strongest storylines as being ones of changing roles and identity as a parent and as a carer.

Gray (2003) spoke to the parents of children and young adults with AS or HFA and compared the responses between the mothers (n=32) and the fathers (n=21). Gray (2003) reported that there was a difference in the personal impact of ASC, in that, though fathers talked about the severe difficulties they said that this did not have a significant personal effect, but rather an indirect effect through the stress experienced by the mother and the impact on the marriage. Gray (2003) suggests that the less severe impact on fathers may partly be due to their gender role of working rather than child raising. Fathers reported little impact on their working life, but rather saw work as providing another role for them outside of the family. Fathers saw themselves as a reserve of support for their wives in times where their wives couldn't cope alone.

3.2.2 Qualitative research with Mothers

Carrington and Graham (2001) interviewed two teenagers and their mothers about AS and perceptions of school. Using an inductive approach of constant comparison they developed four

themes from these interviews: “Developmental differences”, “Problems associated with characteristics of AS”, “Stress” and “Masquerading”. Their study highlighted the impact of social communication difficulties, the difficulties and advantages of obsessive interests and the psychological stress associated with ‘masquerading’ at school. The authors recognise the small sample size and lack of generalisability in the study.

Lutz, Patterson and Klein (2012) conducted a narrative study looking at sixteen mothers’ stories around coping with ASC and the diagnosis. They suggest that the mothers all went through a similar journey of acceptance, using their coping skills to adapt to the “curveball” of the ASC diagnosis. They suggest that mothers initially reacted to the diagnosis with grief and anger and to cope with these feelings they sought answers about the cause and what they could do to help. The authors suggest that mothers experienced “disharmony or distress” on the three dimensions of: psychological, physiological and social. They coped with this distress through seeking support, socializing and through spiritual means. Mothers spoke of their feelings of guilt and doubt about how they balanced family life and the support they sought for their child. Mothers spoke of ASC coming to define the life of the whole family in both positive and negative ways. Disappointment and sacrifice were described by the mothers in the study, as they came to terms with the diagnosis and with their child, but they also spoke of revising their plans to suit the child and planning for the future. Lutz et al. (2012) suggest that these difficulties and coping skills are part of the journey to adaptation. Corman (2007) in a phenomenological study also found that the “joys” of caregiving can help mothers in the stress-coping process.

Gill and Liamputtong (2011) conducted a thematic analysis on interviews with fifteen mothers of children with AS, along with analysis of diaries from some participants. They found that the mothers felt they were often inadequate when they held themselves against their own and society’s expectations of the ‘mother’. They described feelings of guilt if they either chose to continue working, or if they found time for themselves, they described a “duty” to be at home. Where the mothers chose to put their families before themselves, they reported negative health outcomes for themselves. Mothers said that they feel the need to appear to others that they are always coping with being a mother of a child with AS. Mothers reported that they experienced both self-blame and blame from professionals for their child’s behaviour, but that the diagnosis helped them understand the causes.

3.2.3 Qualitative research with Fathers

Donaldson, Elder, Self and Christie, (2011) comment on their clinical experience of fathers reacting: “differently than mothers, tending to focus on the broader, practical implications of childrearing such as cost of care, developmental milestones, and securing provisions for the child’s future” (p. 200).

Donaldson et al. (2011) looked into the perceptions fathers have of their roles in raising a child with ASC, in relation to an in-home programme to improve parent-child interactions. Using thematic analysis they found that five themes emerged from their interviews of the ten fathers of young children. The first theme, "Sharing time", emerged in response to a question about times that they have felt like a father. The authors describe the importance that fathers placed on feeling they had the attention of their child in this time. The second theme, "Having a close relationship", was linked to feeling that they could meaningfully interact and communicate with their child, in a two-way interaction. The third theme, "Accepting the diagnosis", captured expressions of both relief in the knowledge of what was happening and also the loss of the expectations that the fathers had held for their children. The fourth theme, "Concerns of, and Hope for, the Future", was communicated by the fathers in their fears about whether their child would be able to live independently and whether they would be accepted. The final theme reported on the fathers' positive experiences of the parent-child interaction programme.

Keller, Ramisch and Carolan, (2014) also explored the relationships of fathers of children with ASC with their child. They interviewed seven fathers of children aged four to six years old and using a phenomenological approach to analysing the interviews they developed seven themes. Fathers spoke of "Shared activities" and the importance of time spent together. Fathers felt they needed to be "Developmentally sensitive", in helping their sons to learn and develop and they focused on the small achievements along the way. "Emotional understanding" describes the non-verbal communication of love and understanding of their children's emotions. They described having to "Fight the label", to advocate for their children as individuals and talked of their "Fatherhood expectations", of recreating experiences from their relationships with their own fathers and wishes for different interactions with their sons, as well as coming to terms with the diagnosis. "Parent responsibility" refers to the awareness of a balance in their role of parent to other children and in other relationships. "Father isolation" speaks of both isolation from others and within their marriages. The authors recognise the homogeneity of their sample leading to difficulties in generalising their findings, however, they recommend several ways for professionals to help support the father-child relationship and other relationships in the fathers' lives.

O'Halloran, Sweeney and Doody (2013) undertook interviews with nine fathers of children with AS in Ireland. The age of the children ranged from nine years to eighteen years old. Three main themes were identified from the interviews, using a phenomenological approach. The first theme "the journey from awareness to diagnosis" included sub-themes relating to how the fathers became aware that their child might have ASC. The second theme, "Living with a child with Asperger's Syndrome", included sub themes such as rigid routines and fad eating, as well as characteristics such as academic brightness

and a sense of pride. The third theme, “the impact of services”, included aspects relating to a lack of knowledge, waiting lists and financial costs. The authors concluded that the fathers: “expressed huge joy and pride as well as sadness and frustration, and they highlighted the importance of support structures ... in order to appropriately recognise and meet the needs of their child” (p. 14). The fathers in this study were drawn from those using a respite service, which may represent a specific group of fathers with certain attitudes towards the support provided by the service. Respite services for children with Asperger’s syndrome are a relatively rare service, therefore, it could be that these parents are particularly well supported, or experiencing particularly difficult times which need respite care.

Vacca, (2013) interviewed fathers of children with ASC about their pre-natal expectations, post-natal perceptions and their interactions with their child. Using thematic analysis Vacca (2013) identified that the roles that half or more of the fathers anticipated taking were: Breadwinner/ Provider (88%), Caregiver (75%), Teacher (63%) and Organizer and head of the house (50%), (p.86). Fathers reported feelings of denial and confusion at the diagnosis and increased emphasis on the ‘supporter’ role as the father, however, it is not clear in the paper the proportion of endorsement for these themes. Some fathers who already had children reported feeling unprepared for the diagnosis but were relieved to have a better understanding. Fathers reported that they had already adapted their interactions with their children prior to the diagnosis, particularly in play. It is unclear how many fathers took part in this study, as the author indicated that eight people responded to requests for participants, but then further phone-calls were made to enlist more participants. Vacca (2013) undertook this study based upon a previous study (Vacca, 2006) with fathers of children with cerebral palsy. This 2006 study suggested five phases that fathers progress through on having a child with a severe disability; First, a normative phase of expecting a healthy child, then a self-study phase of self-blame, an acceptance phase, a phase to determine aspects of quality of life and finally planning for the future. Vacca (2013) suggests that the research with fathers of children with ASC supports all but one of the phases, with the acceptance phase lacking further endorsement with this group.

Axup (2012) spoke to nine fathers of young adult males (11-19 years) with AS. Using Interpretative Phenomenological Analysis she found six superordinate themes within the context of ‘Self’. “Self in time” reflects the ideas of fathers linking to their own childhoods, seeing the journey with their son as non-static and thinking about the future. Axup (2012) describes “Self and Identity” in terms of challenging norms as: “man, son, father, worker and husband” (p. 109). Participants experienced “gains and losses across all the fathers’ relationships, which influenced their sense of identity and masculinity” (p. 109). “Self-hood and Syndrome” reflects the fathers’ difficulties in living with the unknown causes of AS and how the syndrome affects relationships. Fathers spoke of their experience

of being a father within the context of their marriage and other family under the theme of “Self and family” and within the context of institutions, systems and beliefs in “Self and World”. The final theme “Praxis” considered the fathers’ experiences of being a parent (and all that entails) and working with their partner to parent together. Axup (2012) acknowledges a limitation of the study as the themes were led by the questions that were asked at interview, though this is true to a certain extent with most qualitative research.

3.2.4 Summary of the research with Fathers of people with ASC

Past qualitative research has focused on fathers’ perceptions of their roles before birth and in early childhood (e.g. Donaldson et al (2011) and Vacca (2013)) and on fathers’ relationships with their young children with ASC (e.g. Keller et al (2014)). Some research has involved fathers of children up to the age of 18 or 19 (e.g. O’Halloran et al (2013) and Axup (2012)), but my literature search did not produce any qualitative research undertaken with fathers of adults with ASC. Some research with parents of adults with ASC has been carried out using qualitative methodology (e.g. Griffith et al (2012) and O’Neill (2013)), however, the ‘parents’ were all mothers, apart from a parent pair in each study.

Research with fathers of young children with ASC suggests that fathers anticipate roles such as Breadwinner, Caregiver and Teacher (Vacca, 2013), and that it is important to fathers to share time and have a close relationship with their child (Donaldson et al, 2011, and Keller et al, 2014). Themes around struggles with accepting the diagnosis, and feeling responsible for their child also emerged in these studies. Research with fathers of older children also included these ideas of responsibility and learning to live with the diagnosis and what this means for the child. In addition, there were themes around the experiences of support services and operating within the context of society and its beliefs (O’Halloran et al, 2013, and Axup, 2012). Research with parents of adults with ASC included these ideas of interacting with support services, advocating for their children, and worry about the future (Griffith et al, 2012, and O’Neill, 2013).

3.3 Contribution of this study

Research within ASC covers a large area, the literature review above shows just a small section of this research. The literature review covers some of the quantitative research that has taken place with parents of people with ASC, as well as the qualitative research which has considered the experiences of parents. However, there is a scarcity of research in the areas of fathers’ experiences and viewpoints (Braunstein, Peniston, Perelman and Cassano, 2013) and in the experience of parents of adults rather than children. It is important to build up the picture of the experiences of fathers, as a key member of the family around a person with AS or HFA, a person with expertise in the challenges and joys of

parenting and a person with the right to have support for themselves. Exploring the experiences of a father of an adult with AS or HFA rather than a child, opens up a chance to learn about further challenges and events in a parent's life, for example, as a child transitions into adulthood with all the rights of passage and increased independence this might or might not bring. I consider this study to build both upon the research carried out with fathers of younger children with ASC, and the research undertaken with mothers of adults with ASC.

3.4 Research Question

The overarching question which I aim to explore with this study is:

- What are the Experiences of Fathers of Adults diagnosed with Asperger's Syndrome or High Functioning Autism?

To help explore this question I considered three subsidiary questions, which helped guide the interview process:

How do fathers of adults diagnosed with AS or HFA view and experience:

- Their role and relationships?
- Support for themselves and their child?
- The future?

4. METHODOLOGY

4.1 Introduction

In this section I will discuss the methods used to recruit and interview participants and analyse the data. To put this analysis in context I will describe my epistemological stance and reflect upon personal experiences and beliefs that have led me to undertake this research. I will aim to provide a clear description of the process from the start of the research through to the end of the analysis in order to allow the reader to understand the choices I have made and the steps that have been put in place to ensure the research meets guidelines for quality and ethical research.

4.2 Epistemology

Epistemology is the philosophy of how we come to know things. It is important to consider one's epistemological position in relation to research, as research can be seen as an attempt to come to know more about a particular topic. Sandelowski (2002) suggests that: "qualitative researchers need to explicitly address the status they give to interview data, how they see them and, therefore, how they will treat them." (p.107). I view the interview data from a 'co-constructivist' philosophy. Speed (1991) describes a co-constructivist stance: "[Co-constructivism] takes for granted that a structured reality exists but recognizes that that reality is constructed or mediated in the sense that different aspects are highlighted according to ideas that people individually or in groups have about it" (p. 401).

This is in contrast to a realist position, commonly used in the physical sciences, that there is a single reality, independent of the observer, which can be known (Speed, 1991). It is also different to a constructivist position, where what we know is determined by our ideas, and realities are only constructed in our heads (Speed, 1991). The co-constructivist position appeals to me as, though I believe we construct our perceptions through interactions with objects and other people, I also believe that there is a reality out there to be perceived and interacted with.

I think that a co-constructivist philosophy is compatible with the Interpretative Phenomenological Analysis (IPA) methodology, as IPA explores the participants' interpretations of their experiences, whilst acknowledging that this is being interpreted by the interviewer and analyst. My questions will have highlighted certain areas above others and participants will have talked about some aspects of their experiences and not others. I view the experiences as being constructions of something that has happened in an objective reality.

4.3 Reflexivity

It is impossible to separate the researchers from their research or to be neutral or unbiased. It thus becomes important for researchers to be honest about their histories and reflect upon how that might influence the research (Keller, Ramisch and Carolan, 2014, p.2).

In order to help the reader understand my position and my interpretation of this research it is important for the reader to know a bit about me as the researcher. I am a white-British female who is 29 years old at the time of writing this. I am the youngest of three children and was raised in a graduate and professionally qualified two-parent family and my parents are still together. Growing up, my mother undertook most of the 'caring' and full-time house-keeping roles, whilst my father would be involved in the more 'practical' elements such as helping with homework and mending things, when not working. Given some of the literature mentioned above, I should note that my father is an Engineer. I am not a parent myself, but I have two young nephews and a niece (my brother became a father whilst I was in the middle of this research).

I came to this research through my interest in ASC. Most of my work following my undergraduate degree has been with people with ASC and/or intellectual disabilities. I have met some amazing parents in this time, but have recognised that in my experience it is the mothers that have tended to have been more involved in their child's education or mental health. These contacts with parents of a child with ASC have made me wonder how I would cope if I were to have a child or children with difficulties such as ASC in the future. I think at the start of my career I would tend to judge the parenting of the mothers and fathers of the children I worked with, but over time I have come to be more considerate of the context of the parents and the other things that have influenced their parenting decisions.

I have my own personal experiences of contact with people with AS or HFA (both diagnosed and not) and I am intrigued about the impact of AS or HFA on the experience of the people around them. I am aware of a tendency to view people as 'on the spectrum' if I notice certain behaviours or ways of thinking and I do find that this can help in my understanding of that person. As mentioned in the discussion of the language around ASC above, I view AS and HFA as differences, not disorders and there can be some real strengths that come from ASCs. Personally, I find that I might use the label of 'being on the spectrum' to understand someone and choose how I interact with them, in the same way that I might think of someone as being an 'introvert', rather than as a diagnostic label.

I have been interested in ASC traits since first working with children with ASC, at a special needs camp and then working as a classroom assistant at a school for children with ASC, as there were many conversations between staff of our own "autistic traits", which we could recognise as we saw them in

the children we worked with. This has led me to a strong belief in the top end of the 'spectrum' continuing beyond AS and HFA, with all people having the 'traits' to a greater or lesser extent, whilst still being aware of the challenges faced by people with ASC and their family and friends.

Throughout the interviews and analysis I have tried to 'bracket' my preconceptions. Starks and Trinidad (2007) note that the researcher:

...must be honest and vigilant about her own perspective, pre-existing thoughts and beliefs, and developing hypotheses . . . engage in the self-reflective process of "bracketing", whereby they recognize and set aside (but do not abandon) their a priori knowledge and assumptions, with the analytic goal of attending to the participants' accounts with an open mind (cited in Tufford and Newman, 2010).

I have noticed times, particularly in the transcription process, where I have felt a strong reaction to something a father has said about their child and have noted these reactions for reflection and attention during the interpretative analysis¹. I have returned to these notes as I have conducted the analysis to check that the data supports the emerging themes and it is not purely my preconceptions that have constructed them. The steps taken to ensure the quality of the analysis are further discussed below.

4.4 Qualitative methodology

Smith, Flowers and Larkin (2009, p. 45) describe quantitative research as tending to try and measure "what happens at one remove, by inferring mental events from observations of behaviour". Whereas qualitative research "tends to focus on meaning, sense-making and communicative action" (Smith, Flowers and Larkin, 2009, p. 45). I chose to use a qualitative approach as I was interested in gaining an in-depth understanding of the meaning attributed to a small sample of participants' experiences. A quantitative approach could have gained information from a larger pool of participants, but would have lost information about the depth of experiences. The research around ASC tends to be more from a quantitative viewpoint than a qualitative one. In particular, little has been heard from the fathers of adults with ASC, and as Dallos and Vetere (2005) suggest, qualitative methods: "emphasize rich descriptions of a phenomenon and allow participants' voices to be heard, for example, by providing contextualised verbatim quotes from participants" (p.50).

¹ An anonymised extract from the reflective notes for one participant can be seen in Appendix O.

4.4.1 Why choose IPA?

I considered using Grounded Theory, Discourse Analysis and a Narrative approach before choosing IPA as the most suitable method for this research.

Grounded Theory (GT) (Glaser and Strauss, 1967) is a qualitative method, whereby theories are constructed from the data; the theory is 'grounded' in the data. The process of GT involves ongoing analysis and generation of new data, so that the experience of interviewing and analysing can influence each other in guiding the researcher to examine emerging areas of interest. Smith et al. (2009) talk about selecting GT as a research method:

Grounded Theory is likely to be attractive to you if you have the time and space to deal with a lot of data, if your focus is not necessarily (or primarily) psychological, if you are keen to have a relatively structured protocol to follow... (p.44).

The structured protocol for analysis in GT appeals to me, but within the context of this research being undertaken as part of the Doctorate in Clinical Psychology, I have neither the time or space to deal with large amounts of data and almost by definition, there needs to be a psychological focus for the research.

Discourse or Discursive analyses focus on language itself. Foucauldian discourse analysis is concerned with the power of different discourses in society and how this is reflected in certain communications. Discursive analysis looks at the interactions of communications and the language used (Smith et al., 2009, p.44). I see language as an important part of the communication of an experience and I acknowledge that the power of different discourses is also of interest, but neither is the main focus of my interest in the experiences of fathers of adults with AS or HFA.

Narrative methods of research may focus on content or the structure of a story, or may look at the narratives which exist in society or the stories we tell ourselves (Smith et al., 2009, p.44). I carefully considered a narrative approach, as the time structured element of a story seemed to fit the information that I wished to explore. In part I did not choose to conduct a narrative analysis as I was more drawn to the content aspect of narrative analysis, which seemed better explored through IPA. I also did not find that the narrative method was compatible with my need for a fairly structured analysis protocol, as a new-comer to qualitative research.

It was IPA's focus on the 'particular' that most appealed to me, as I anticipated some varied experiences between the fathers I would be interviewing and I wanted a method that would capture the individual voices as well as the experiences that they have in common.

4.5 Interpretative Phenomenological Analysis (IPA)

“IPA is concerned with the detailed examination of human lived experience” (Smith, Flowers & Larkin, 2009, p. 32). The aim of an IPA study is to explore the participants’ interpretation of their personal and social experiences. However, as Smith and Osborn (2007) comment: “The participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world” (p. 53). As the researcher’s interpretations are influenced by their own understanding of their own experiences an important part of the IPA process is the researcher’s reflexivity.

IPA is a qualitative method which was developed by Smith to be an approach: “which was able to capture the experiential and qualitative, and which could still dialogue with mainstream psychology” (Smith et al., 2009, p.4). Smith et al. (2009) describe the theoretical foundations of IPA as: “being informed by concepts and debates from three key areas of the philosophy of knowledge: phenomenology, hermeneutics and idiography” (p. 11). These three areas will be briefly described below.

4.5.1 Phenomenology

“Phenomenology is a philosophical approach to the study of experience” (Smith et al., 2009, p. 11). It was first founded by Husserl in the early 20th century in order to try and find a way of examining the essential qualities of an individual’s experience, without altering that experience. Husserl also acknowledged the need to ‘bracket’ assumptions about the world before trying to examine the perception of experience (Smith, Flowers and Larkin, 2009). In describing the process of the development of Phenomenology Smith et al. (2009) comment: “we have come to see that the complex understanding of ‘experience’ invokes a lived process, an unfurling of perspectives and meanings, which are unique to the person’s embodied and situated relationship to the world” (p. 21).

Giorgi and Giorgi (2008) comment that: “phenomenology aims to remain as faithful as possible to the phenomenon and to the context in which it appears in the world” (p. 28). This means that the phenomenon must be examined in a person who has lived experience of the phenomenon. However, a person’s account of an experience will be their interpretation and any analysis of this account will require a further level of interpretation. The theory of interpretation is called Hermeneutics.

4.5.2 Hermeneutics

Smith et al. (2009) write that Hermeneutics started with scholars who were interpreting historical documents in order to consider the meaning of the document in the context of the time it was written

and the time that it was being interpreted. Heidegger, a student of the phenomenologist Husserl, extended the thinking on phenomenology to consider the hermeneutic element. Smith et al. (2009) write of Heidegger's theories: "the reader, analyst or listener brings their fore conception (prior experiences, assumptions, pre-conceptions) to the encounter, and cannot help but look at any new stimulus in the light of their own prior experience" (p. 25).

The concept of the hermeneutic circle is important when considering IPA, as it helps a researcher to think of the levels of interpretation that need to be conducted. The hermeneutic circle suggests that: "to understand any given part, you look to the whole; to understand the whole, you look to the parts" (Smith et al., 2009, p. 28). This is a circular, dynamic relationship and these 'parts' and 'whole' may operate on many different levels as well, as for example, a part might be a single sentence in the whole of an interview, but that interview might be a part in the whole of the research study.

4.5.3 Idiography

An idiographic approach to understanding experiences focuses on: "the interplay of factors which may be quite specific to the individual" (Ashworth, 2008, p. 14). In contrast to this, the nomothetic approach is based on the idea that there are general laws that determine why people might behave in certain ways and so these general laws are discoverable and quantifiable. A nomothetic approach would tend to examine a phenomenon in a large number of people in order to draw generalizable conclusions, whilst an idiographic approach might look at a smaller sample of people, in order to look at the particulars of their experiences.

4.6 Participants

4.6.1 Recruitment

Recruitment took place through support groups for parents of people with ASC. Emails requesting support with recruitment were sent to the contact email addresses of several support groups in the South and East of England. The contacts were asked to pass on the participant information sheet (Appendix C.) to any group members who might be interested in participation. I also attended one local group meeting to explain the project and this was offered to all groups contacted. An advert for recruitment was also placed on the National Autistic Society's web-page and on a number of online support forums, but no participants were recruited through these means.

Macfadyan, Swallow, Santacroce and Lambert (2011) discuss some of the difficulties of recruiting fathers for research. They recommend that it is made clear that the views of fathers are valued in the research, as fathers: "may not appreciate that their views are valued, and they can assume that the

mothers' opinions may be more relevant" (p.217). It was therefore made clear in both the initial recruitment adverts and the participant information sheet that this research was focused on hearing the experiences of fathers.

4.6.2 Inclusion and exclusion criteria

Due to the nature of IPA, researchers using this method generally use a purposive sampling method to gain a homogenous sample (Smith & Osborn, 2007, p.56). A homogenous sample is important for this study as all of the small number of participants need to share the experience of being the father of an adult with AS or HFA.

Recruitment was targeted at fathers living with their adult child with a diagnosis of AS or HFA. 'Adult' was considered to mean 18 years of age or older. Participants did not have to be biological fathers, but had to consider themselves to be in the father role and have been in that role since before their child was diagnosed.

Exclusion criteria for participants were if the father did not speak fluent English and if the adult child was not living at home with the father. Fathers would also be excluded from this research if their adult child had a diagnosis of intellectual disabilities, as I felt that this would add in very different experiences of fatherhood. I did not exclude participants where the adult child also had a diagnosis of a mental health difficulty, as mental health difficulties are common in people with a diagnosis of AS or HFA (Attwood, 2003).

If fathers confirmed that they believed themselves to meet these criteria they were accepted in the study.

4.6.3 The sample

Through the recruitment method detailed above, seven participants were recruited for the study. I was contacted by ten fathers in response to the requests for participants. One of these fathers did not respond further after initial contact by email. One father no longer lived with his adult child and so did not meet the inclusion criteria. The final excluded father was an adult with ASC with an infant child. Demographic details of the fathers and their families can be found in Table 1. Specific details have been changed or generalised to help preserve anonymity for the participants.

Table 1.

Demographic characteristics of the sample

Participant number	Father's 'Name'	Father's Age range	Father's occupation area	Adult child's gender	Adult child's 'name'	Adult child's Age range	Adult child's occupation area	Other children	Spouse's 'Name'
1	Peter	50-54	Technical	Male	Simon	22-25	None	None	Jill
2	Ben	60-64	Finance	Male	Nathan	18-21	None	None	Sharon
3	Sam	75-79	Retired, journalism.	Male	Mark	32-35	Retail	Two sons	Maria
4	Henry	45-49	Health	Female	Janet	18-21	Student	One daughter, one son.	Rita
5	Andrew	65-69	Finance	Male	Don	22-25	Education	One son	Kate
6	Charles	50s	Finance	Female	My daughter	18-21	Student	None	My wife
7	Mike	60-64	Retired, Retail	Female	Angela	22-25	Administrative	One daughter, one son.	Tracey

4.7 Ethical considerations

This study was approved by the University of Hertfordshire's Research Ethics Board. The protocol number is: LMS/PG/UH/00247.²

4.7.1 Informed consent

Potential participants were provided with a participant information sheet (Appendix C.) prior to meeting for the interview and encouraged to ask any questions. Participants signed the consent form (Appendix D.) before the interview, which further ensured that participants were aware of areas such as confidentiality, anonymity and their right to withdraw at any time. Participants were provided with contact details of the researcher, supervisors and the head of the Ethics approval board at the University of Hertfordshire, in case of queries or complaints.

4.7.2 Confidentiality and anonymity

Participants were informed that all possible measures would be taken to protect their anonymity and to keep their information confidential. However, they were also informed that due to the small community nature of some support networks there would still be a small chance of identification, which all participants accepted. Confidentiality and anonymity were ensured through protection of data and transcripts that might include identifiable information and changing of any identifiable information in the last stage of transcription. Participants were informed that all transcription would

² The approval notification and approval of amendments to the ethics application can be seen in Appendix A.

be carried out confidentially. Participants were informed that the digital recordings of their interviews and any other identifiable information would be kept securely until the conferment of the professional qualification that this research forms a part of. At this point they will be destroyed securely.

4.7.3 Safeguarding

GP (General Practitioner) details were taken from all participants before the interview in case of concerns about safety of the participant or their family. They all agreed to give these details and it was not necessary to use these contacts for any participant.

4.7.4 Potential distress

It was not anticipated that the interviews would cause any undue distress. However, as fathers were talking about experiences that could be difficult for them, time was given after interviews for questions and support. Participants were also provided with a de-brief sheet (Appendix E.) with researcher and supervisor contact details and with details of support groups in their local area. If participants were to become very distressed during the interview the planned protocol was to allow the father the choice of continuing the interview, taking a break and continuing the interview later, or stopping the interview and rearranging for another time; it was not necessary to use any of these measures during the interviews. I have experience of working with people who are in distress and would have made use of this if needed. If I had become concerned about someone's mental wellbeing I would have either used the GP contact details, or stayed with the participant until a family member returned home.

4.7.5 Safety of researcher

As the interviews were conducted at a place of the participant's choice, details of the participant and the interview were sent to my supervisor in a password protected document, only to be opened if contact was not made after the interview.

4.8 Data Collection

4.8.1 Interview development

Smith and Osborn (2007) describe the semi-structured interview as "the exemplary method for IPA" (p. 57). The semi-structured interview allows some flexibility to follow up what is being said to gain a more in depth understanding of the experience, whilst also providing the structure to ensure that the interviewer covers all of their planned questions. Questions in a semi-structured interview for the

purpose of IPA should be: “prepared so that they are open and expansive; the participant should be encouraged to talk at length” (Smith, Flowers and Larkin, 2009, p. 59).

The semi-structured interview was developed following an initial search of the literature. The interview schedule used by O’Neill (2013) was used as a guide for areas to be explored in my interviews. O’Neill had developed these areas of questioning in collaboration with a focus group consisting of members of a support group for families of people with ASC.

My semi-structured interview schedule was shared with attendees at a local coffee morning for parents of people with ASC. The parents reported that the interview schedule was likely to cover areas that they would deem important in their experiences of parenting and that the questions were clear and easy to understand. The parents did not offer any suggestions of changes. The interview schedule can be viewed in Appendix G.

A pilot interview was conducted with a father of an adult with AS and the interview schedule was not deemed to need any changes; this pilot interview is therefore included in the analysis, as Peter’s interview.

4.8.2 Interviews

Before interviews commenced participants were offered the chance to ask any questions, demographic and GP details were taken and they were asked to sign the consent form. Participants were made aware that they did not have to provide demographic information, but that GP contact details were needed in order to proceed with the interview for safeguarding reasons. After the interview participants were offered the opportunity to ask any questions and provided with a de-brief sheet.

Interviews took place at a location of the participant’s choice. Two interviews were conducted at the participants’ workplaces. The remaining five interviews took place at the homes of the participants. Six interviews were conducted in one session, but one interview took place over two sessions a week apart due to a lack of privacy threatening anonymity. Interview times ranged from around fifty minutes to two and a half hours.

4.8.3 Transcription

Identifying details were removed or changed as the final stage of transcription. Transcription in itself can be viewed as an interpretative process, so I felt it was important to carry out the transcription myself.

4.9 Data Analysis

The data was analysed using the IPA method described by Smith and Osborn (2007):

1. The transcript is read and re-read, noting exploratory comments in the margin. Exploratory comments are notes on things that are of interest in the text.
2. These exploratory comments are then developed into the emerging themes. Emerging themes are “concise phrases which aim to capture the essential quality of what was found in the text” (p.68).
3. The connections between themes are then used to group the themes into clusters where the themes are closely linked.
4. The super-ordinate themes are identified. These are the themes that link a cluster together.
5. A table of the super-ordinate themes for one interview is constructed, with examples from the text of where this theme is evident.
6. This process is repeated with the other transcripts. The themes from the first interview analysed are used to identify similarities and differences in the next interview. With each subsequent interview analysed a picture of the links, connections and differences in experiences can be built.
7. The individual super-ordinate themes from each account are then listed and clustered. Some of these themes may be combined if they capture something of a similar experience. The themes that tie each cluster together become the group super-ordinate themes.³

4.10 Quality measures

Yardley (2000) presents four criteria by which to measure the quality of qualitative research. These are: Sensitivity to context, Commitment and rigour, Transparency and coherence and Impact and importance, (Yardley, 2000, cited in Smith, Flowers & Larkin, 2009).

4.10.1 Sensitivity to context

The sensitivity to context criteria was met in this study through a thorough consideration of the relevant literature and the context of the research within studies of ASC. Dallos and Vetere (2005) recommend a triangulated approach to validity, which includes a thorough literature review. The interview schedule was based on one constructed with a focus group of people living within the context and my own schedule was approved by a group of parents of people with ASC. A semi-structured interview was used to be flexible to the experience of the participant and open-ended

³ Appendices H-N show this process for ‘Charles’ and results for the whole group.

questions allowed for participants to answer with as much or as little information as they wanted to. The data have been analysed with attention to the bracketing of my own assumptions and with sensitivity to what emerged from the data, rather than a pre-determined idea of what should be there. My supervisors have offered the viewpoints of a father, of an experienced professional working with people with ASC and of a parent to someone with ASC.

4.10.2 Commitment and rigour

Commitment can be seen in the time and effort put into transcribing and analysing the interviews in depth. Rigour has been exacted in the selection of a homogenous group of participants, who were selected to match the research question. The process of my analysis was thoroughly checked by my supervisor, who is very experienced in the use of IPA and in supervising qualitative research. My supervisor also scrutinised the analysis to ensure that it was sufficiently interpretative and to check that the results can be clearly traced back to the interview data. He can therefore be seen as an 'Independent Auditor' validating "the coherence and relevance of an existing analysis" (Dallos and Vetere, 2005, p.208). This involved my supervisor looking at all stages of analysis of one transcript and looking at the overall results in relation to his knowledge of the transcript and the individual super-ordinate themes from each interview. We met to discuss any differences in opinion about the analysis and to explore reasons for interpreting data in certain ways. A peer IPA group also considered shorter sections of the analysis in the initial stages.

Samples from the interviews are used to support any interpretations made and attention is paid to ensuring that interviews from different participants are given equal weight in support of themes.

Elliott, Fischer and Rennie (1999) suggest in their guidelines for reviewing qualitative research that researchers should provide checks of credibility. In addition to my supervisor and IPA group viewing the analysis, readers of this research can view the Audit trail in Appendix H-N to judge the credibility of my interpretations. The super-ordinate themes were also checked for credibility by my field supervisor, who has extensive experience of working with people with ASC and their families. The decision was made to not 'member check' the interpretation with the participants themselves. As Sandelowski (2002) suggests:

...member responses... cannot simply be treated on their face as the best measure of the trustworthiness of research findings. Members may, for example, forget what they have said, regret what they have said, feel compelled to agree with researchers, or, as we all do, have the need to present themselves in different ways at different times (p. 108).

In addition, analysis may bring out themes that are not within the awareness of participants, or could be difficult to acknowledge as being visible to others in their accounts. I also view my analyses as one possible interpretation of the transcripts. Others could interpret the data differently and each interpretation would still be valid: “Even if another researcher or a research participant produces another version, it does not invalidate the researcher’s version, it merely adds another plausible description” (Bradbury-Jones, Irvine and Sambrook, 2010, p.28).

I have taken steps to ensure that my analysis of the data has been systematic and rigorous and I am confident in the quality of my interpretation; methodological limitations of this research are reported in the discussion section.

4.10.3 Transparency and coherence

I have aimed to be transparent throughout this process, detailing the stages of this research and analysis. Coherence is generally judged by the reader of the research. Efforts have been made to present a coherent argument for the need for this study and to present the process and my interpretation clearly.

4.10.4 Impact and importance

It is hoped that this research will be of use to both professionals and to the fathers themselves, through acknowledgement of their roles and knowledge of the experiences of others.

5. RESULTS

5.1 Introduction

In this chapter the results of the Interpretative Phenomenological Analysis of the interviews with the seven fathers of adults with AS or HFA will be presented. The group super-ordinate themes and their sub-themes will be explored, with examples from the transcripts of the interviews.

Four group super-ordinate themes emerged through the analysis of the seven interviews:

- The changing role but constant responsibility of being a 'Father'
- The importance of knowledge and understanding
- The intense emotional impact
- The importance of good support.

Table 2 below summarises the four group super-ordinate themes and the sub-themes that combined to create them.

Table 2.

The group super-ordinate themes and sub-themes.

The changing role but constant responsibility of being a 'Father'	The importance of knowledge and understanding	The intense emotional impact	The importance of good support
<ul style="list-style-type: none">• I would have done whatever was necessary• Life has changed, role has changed: we're looking at a journey• You know the difference between men and women?	<ul style="list-style-type: none">• Typically different• Diagnosis: a road map or a bereavement?• Just having that knowledge makes a big difference.	<ul style="list-style-type: none">• Seeing my child suffer was testing and it was painful• The ability to provoke that intense emotion• Getting away from all the issues at home• Those other events have shaped quite a lot that has happened	<ul style="list-style-type: none">• Perpetually badgering for support• With support life can flourish, but we've had nothing• Maintenance or collapse of exterior world

This section will illustrate and explain the themes with verbatim extracts⁴ from the transcripts of the seven interviews. The account of the themes described below aims to explore the similarities and differences between the fathers' experiences.

I recognise that this understanding of the interviews is only one way of interpreting what was said. I believe that I have presented a coherent and plausible account of the experiences described by the fathers. I have also aimed to be transparent about the extent that the questions asked in the interviews may have directed fathers towards certain topics. The interview questions were designed to open up topics for discussion, without making any suggestions as to the quality of an experience.

5.2 The changing role but constant responsibility of being a 'Father'

The theme of 'the changing role but constant responsibility of being a 'Father'' reflects the stories of change that ran alongside the narratives of life-long responsibility for their child. Most fathers also spoke of their roles in terms of being a man and the expected roles for their wives. Questions in the semi-structured interview were directed towards how the fathers perceived their role and if this had changed over time, but this theme emerged naturally from stories expressed throughout the interviews, not just in direct response to these questions. Three sub-themes grouped together in the analysis to create this super-ordinate theme: 'I would have done whatever was necessary', 'Life has changed, role has changed: we're looking at a journey' and 'You know the difference between men and women?'.

5.2.1 I would have done whatever was necessary

The responsibility the fathers felt they held for their children was a common theme throughout the interviews. The fathers described feeling a responsibility to give their children what they need and to support them into independence. The idea of having a responsibility to give independence was particularly strong for Charles. For example, he described his 'crusade':

The crusade we used to call it, this (...) insatiable, unquenchable desire to make my daughter independent.

Ben spoke of 'finding pathways' and working behind the scenes to get his son 'doing things', whilst Sam was 'getting rid' of his son to a shared house to support his independence. Henry described

⁴ Details have been changed in order to protect the anonymity of the participants, whilst not changing the meaning. Repeated words and words such as 'um' and 'err' have been removed for readability. To improve clarity and readability words in [square brackets] have been added to give extra information. Where information is not considered pertinent to the meaning and interpretation, missing words are indicated by ellipses (...).

learning to let his daughter handle her own life, whilst feeling a 'pressure' to predict and protect her from upcoming stresses:

I feel it should be my job to anticipate what problems might arise for her, and that's quite a struggle as well, because of course she doesn't always agree.

Andrew described his son as becoming 'largely self-sufficient' but still feeling responsible for him, but, like Henry there was a difficulty as Don didn't agree with this responsibility:

I still feel responsible for him, but he doesn't think I am.

These differences of opinion between the fathers and their children seemed to me to be the typical struggle that comes about when a parent needs to let go of some of their responsibility as their child becomes an adult and strives for more independence. These fathers seemed to have some reluctance to let their child have this full independence, perhaps as they viewed their child as more vulnerable or less able because of the AS or HFA.

Mike described his whole life as being "modified" because of his daughter and Sam described the impact of this responsibility on him and his wife:

The whole time we have to be thinking, how does Mark fit into this arrangement or that arrangement? He's still in our care, in many, many senses of the word.

These ideas that all the fathers' lives had been significantly changed by the responsibility of caring for their child suggested a certain willingness to adapt in order to care for them, with their "best interests at heart" (Mike). Though the fathers spoke of the huge impact of feeling responsible for their child at all times, there was not a sense of regret or frustration about this for most of the fathers, but rather a sense of acceptance. Andrew described this in terms of any parent:

If you have children you take on a big responsibility but you don't know what it's going to be like until you get there.

Peter summed up the ideas of responsibility and protecting his son, a theme which emerged throughout every interview, with the following phrase:

I would have done whatever was necessary.

I feel that this comment could have been made by any of the fathers that I interviewed and all of the fathers spoke about how they did do "whatever was necessary" at different times in their children's lives, such as Peter sitting in his son's room whilst he did homework, Ben driving up to Scotland as he was concerned about his son and Sam fighting a legal battle with the council to get his son into the school he wanted.

All of the fathers spoke of their responsibility to support their children, but this took on slightly different forms between parents and at different times in their children's lives. For example, with the drive to make their child independent mentioned above some fathers, such as Charles, felt it was their responsibility to give skills to their child so they could be independent:

I'm thinking as a father I've got to bring this person on and give her the skills that I think she needs to navigate through life. Skills that I've got that I want to give.

Charles spoke of this attitude coming from his feelings that this was what she would need to be successful. There was a strong sense that he felt his daughter needed to do the same things he had done in order to have a good life. This was an attitude that changed for Charles through Family Therapy and he later described being able to let his daughter try her own ways of managing things:

Just let her make that mistake (...) she might learn from it.

For both Andrew and Charles there was a sense that they would let their child be independent up to a certain point, but would be ready to jump-in if they felt their child was about to do something "daft". Henry took a slightly different approach, in that he talked of a "balance" of letting his daughter do what she wanted, whilst also wanting to give advice and talk things through before she decided:

I want her to see that if she is stressed about something, that she can (...) come and tell me and discuss it with me, and I will tell her what I think, but I do actually respect that she has to make her own choice.

Henry spoke of finding ways to direct his daughter towards what he viewed as the better course of action through less direct methods. This is also something that Ben described, as he found that if he took too much interest in his son's choices then his son would lose interest in them. Ben describes having to work in the background instead:

You can't even take the horse to water, you know, I mean, (...) I was absolutely Machiavellian in my attempts to try and get things linked and sorted.

There was a sense that these five fathers were, on the surface allowing a certain amount of independence, whilst manipulating some things in the background in order to steer their children in the direction they thought best.

For Peter and Mike, this strive towards independence was not present in their narratives. In Peter's story there was more a sense of rescuing his son from difficult situations and sorting things for him, rather than a promotion of independence:

It's that sort of thing [a shop assistant]. I have to go rescue [him] from, problems.

For Mike there was an impression that he would try and shield his daughter from experiencing anything that could upset her and so preventing situations where she might struggle:

EastEnders has just got so dreadful, we've eventually persuaded her to stop watching it because she used to get worried.

There also seemed to be a sense of fathers protecting their children by not discussing certain things in front of them in case they found it distressing. This was particularly clear in the interviews where the fathers were anxious that the interview was not overheard by their child (Ben, Henry, Andrew and Mike). The extent of this varied, as some fathers were very worried that their child might learn about the interview at all, whilst others just didn't want their child to hear exactly what was said. Mike said this about his daughter:

If she'd been anywhere in the house she'd have been listening. And though I shall tell her all the stuff we've talked about, it's best that she doesn't actually listen to some of the detail.

These different strategies of supporting, rescuing or shielding, seem to me to all be ways of protecting their children from, as Sam put it, the "next trauma the world has to throw" at them. Most of the parents spoke about how they felt this responsibility to protect their children would continue after they died. They spoke about their plans for the future and taking steps now to ensure the continued support and protection of their children. For example, several fathers spoke of learning about setting up their wills so that their children would have financial security when they die. Ben said:

The last one [lecture] I went on was a lawyer speaking about, (...) it's very important, trusts and trying to provide (...) and how to provide. We went there desperate to hear what we might do.

There was also a sense that responsibility for looking after their adult child would need to pass to another person when they died. Sam spoke of this responsibility passing to his youngest son:

James, being the straight-forward young man he is, is going to end up with a lot of responsibility, which is quite unfair, but knowing him, he'll take it on.

This seemed to be the case for all the families where there were siblings who would be able to take on the responsibility. Sam also spoke of setting up trustees, but struggling to find people that he would trust with this role.

5.2.2 Life has changed, role has changed: we're looking at a journey

The stories of all the fathers reflected a series of changes in their lives and the lives of their children and hence in their role as a father. Peter, Ben and Henry's stories gave an overall impression of many

ups and downs, with some progress in places. Sam, Andrew, Charles and Mike's stories suggest more of a clear progression from a place of difficulty to an easier place.

We're looking at a journey, and there has been progress. If I remember how she was... (Charles)

These stories of progress reflected changes in their children's behaviour as well as a development in their understanding of their child, which will be discussed later.

Peter, Ben and Henry spoke about how their roles might be different when their children were in different places emotionally. These three parents also reported that their children had diagnosed mental health difficulties and the 'downs' appear to mostly describe times when their child was feeling particularly low and exhibiting behaviours congruent with a diagnosis of depression and/or anxiety. These behaviours included isolating themselves, losing interest, misusing substances, self-harming and taking overdoses. Henry described how he feels that his role in these very difficult times is to find help for his daughter:

When she reaches that crisis (...) that's when I feel I need to say to her that you do need some more help.

During these crisis points it seems that each father's understandable instinct is to find some extra support in order to keep their child safe. There was a sense of deep frustration from Henry that his daughter was not accepting any extra support at these times.

Ben spoke of how his role has changed as he feels that what he has been doing hasn't been that helpful. He feels that his father role is a "non-role" at the moment:

I don't think it helps at all now to try and help, I don't try and help (...) I mean I do care, but I don't try and help.

There was a sense when Ben was speaking of this that he was in fact seeing if taking this step back would be helpful in itself.

Peter spoke about the temptation to "not bother" when things are at their most difficult:

We try to keep his daytime routine going, but it gets to a point where it's such hard work that you're going to start not bothering.

Though Peter spoke about this a couple of times, the impression I got was that these times were not the norm and there was a careful weighing up of the consequences of "not bothering" before he would do this. I thought that Peter felt that there were times when his own and his wife's well-being had to come first. This sense also came across in Ben's experiences.

Those fathers whose stories reflected big ups and downs in their lives spoke of how their role was different when things were going well for their children. For example, Ben spoke of his role when his son was motivated and engaged in looking for a job:

He came to me, to work through his application forms and all that (...) so we were working quite well, (...) I did have a sort of father role for a period of time.

All of the fathers that spoke of these positives conveyed a sense of passion and enthusiasm when describing how they were really engaged with their child in these times. This was balanced with a sense of loss when this engagement wasn't happening.

Some fathers spoke of the difficulties of trying to keep their child in a good place emotionally. Henry spoke of an "emotional switch" rather than an "emotional dial" and that there was "no credit in the bank". Mike also spoke of this difficulty with his daughter:

It's difficult to make her happy, very easy to make her unhappy.

Throughout the interviews with these fathers it was apparent that they and their families were walking a fine-line in order to try and keep their child happy and there was frustration when, despite a week of positive experiences, one negative could ruin the entire week in the eyes of their child.

Most fathers spoke of how their children had learned to react to things in different ways as they have grown older, which means that certain roles they have held, such as restraining, calming or disciplining, have become un-necessary. Speaking of his role of calming his son down, Sam said:

Obviously my life has changed because that is no longer necessary.

Whilst certain roles decreased, the fathers spoke of other roles increasing as other ways of interacting became possible. Mike spoke about how his interactions with his daughter have changed:

So when she was younger she could be totally irrational, there was no way you could actually deal with it, but nowadays I feel I can, so I think that side of my role has increased.

This comment from Mike reflects a feeling that some of the father-child interactions improved through the child adapting their ways of interacting in ways that met the styles of their parents. For example, for Mike it is important that people can react rationally, for Ben it is important that his son is engaged in 'doing' things, for Henry it is important that his daughter discusses things with him.

5.2.3 You know the difference between men and women?

All of the fathers except Henry described what might be considered a 'traditional' family arrangement, at least in the early years of their child's life, where they worked and provided for the family, whilst

their wives stopped working and looked after their child. Several fathers spoke of how they could not have performed any other role within their family, particularly feeling that they could not have taken on their wife's role. For example, Charles spoke of his wife:

I was really glad that my wife was doing what she was doing, because I couldn't do it.

There was a sense that the fathers who spoke of this inability to take on their wife's role felt that they would not be able to cope with the intensity of being at home with their child all day.

Comments made by two of the fathers about the focus of this research and the availability of support groups, reflected a belief about mothers being more involved in their children's lives and being more "interesting" (Sam) to interview. Andrew commented:

Mothers are in need of help, because they're stuck at home with the kid.

Andrew acknowledged that this view came from his understanding when growing up that fathers went to work and mothers stayed home to look after the children.

There was a general pattern of the fathers describing their roles in practical terms, wherein they would have certain practical tasks which they performed, such as distracting their child, driving their children around, helping with forms, or giving their wife a break. Where they described their wife's role, this seemed to be more of an emotionally supportive role and of the mother being the one that their child talks to about personal subjects. As Andrew said:

He doesn't talk to me, he talks to his mother about it a little, he talks to me about hardly any.

Sam had particularly clear views about the differences between how men and women might behave. He described differences in the way that men and women approach problems and described ways in which he could talk about his sons in a different way than his wife could:

Cos I'm a man and I can say things like that. I can get away with it, she couldn't.

Charles frequently spoke about how what he was doing was a natural way for men to behave. He compared his reactions and his wife's and generalised to all men and women:

It [talking] doesn't come naturally to guys. Guys just want to go off in their cave I think.

5.3 The importance of knowledge and understanding

The theme of 'the importance of knowledge and understanding' is a theme that arose in all the interviews with the fathers, as they described their developing understandings of their children, their perceptions of their children and the importance of other people understanding them. There are three

subthemes that contributed towards this super-ordinate theme: 'Typically different', 'Diagnosis: a road map or a bereavement?' and 'Just having that knowledge makes a big difference'.

5.3.1 Typically different

As the fathers talked about their experiences, they referred to their children in different ways, which seemed to me to reflect how they perceived their children. Most of the fathers referred to their children as 'different' because of the AS or HFA:

Don is different. Because he is autistic. (Andrew)

He was different, and he knew he was different. (Peter)

Yes he's different, delightfully different, some of us think. (Sam)

The fact that she was different... (Mike)

Fathers seemed to view the 'difference' of their child in diverse ways. For example, Sam described his son as "delightfully different" and said that he "wouldn't have him any other way". With some of the other interviews there was more of an impression that the difference was a negative thing.

All of the fathers commented on the strengths of their children and showed pride in their achievements. For example, Mike said:

The greatest thing about Angela is that she doesn't give up. She's a real tryer, as evidenced by all the qualifications she's got. She's far more qualified than many.

The fathers talked about their children's strengths in areas such as academics, sport and their abilities to get on with other people. Some of these strengths appear to have masked the difficulties that their children experience. Some of the fathers spoke about the different perceptions other people may have of their children, which can lead to misunderstandings of the difficulties. For example, Charles talked about how other people see his daughter:

You'd be, in common with most of the rest of the world, you'd say that's a lovely young women (...) what's the problem, you know, what's the problem?

For Charles there was a sense that these different perceptions of his daughter were often frustrating for him, as it led to less understanding of the difficulties that he was experiencing at home. Peter also spoke about worrying about how his son would come across to other people in assessments:

Go to the doctors and you know, 'Oh, isn't he fine' (...) but he's at home, he's screaming his head off.

Some of the fathers also spoke of the challenge of communicating their child's difficulties when they have been completing forms for support. Peter said:

[It is an] absolute nightmare filling in the forms. Cos you can't say 'his brain works at 10 million times faster than most people's brain does'. You can't put that on a form.

Charles also spoke about the gruelling nature of having to fill in forms with details about his daughter's difficulties:

To speak about your daughter in the terms that are needed for a disability living allowance application, or a statement or any of that stuff, you have to spell out the bad stuff, and leave them in no uncertain terms about the effects on that person's life. It is gruelling.

Some of the fathers had developed metaphors and images to help them understand their child's difficulties and to help them explain the difficulties to others. For example, Charles said:

If you could imagine life as a platform and we're all walking along on an equal footing, the platform is flat for us. For someone like my daughter there's a gradient on this platform. Just to operate normally she's having to put work in.

This metaphor of how life is for his daughter seemed to have really helped Charles in his understanding of why she finds some things difficult, or might become overwhelmed by small things. Peter described his perception of how his son operated in the world, which seemed to help Peter understand why his son might react a certain way to situations:

Our worlds overlap quite a lot, but his bubble is his own territory. Like this bloke in Boots. He invaded his territory and he couldn't cope with it.

Some of the fathers talked about their child in terms of them being 'typical Asperger's'. These fathers spoke of their knowledge of what Asperger's is and would compare their child to the 'typical'. Peter described his son:

He was a typical Asperger's type person in his early years. He was very into dinosaurs, which is the typical thing with Asperger's.

Mike also spoke about some of the difficulties his daughter experiences in terms of Asperger's "symptoms":

So yeh, just about everything you can put on the Asperger's list of typical symptoms. She's got them.

The fathers that spoke about this 'typical' Asperger's seemed to gain some reassurance that their child was 'typical'. This is perhaps because of the wealth of information and support on how to manage 'typical' behaviours.

The fathers of daughters with AS or HFA spoke about how things were different for females on the spectrum, compared to males. For example, Mike spoke about his daughter's tendency to apologise a lot:

She apologises constantly for doing things, when there's nothing wrong, which is a typical Asperger's trait anyway, to say sorry all the time, particularly for girls.

Mike also spoke about the difficulties of getting a diagnosis for his daughter:

Part of the problem was, I think females present differently to males, her social capabilities were zero pretty much, but she was, I think, quite clever in other ways.

It seems that being "quite clever" had perhaps helped Mike's daughter to develop some compensatory strategies that may have masked the ASC. Or perhaps Mike felt that she was not diagnosed as there is less concern if a child appears to be succeeding in other ways, whilst perhaps the social aspect was not valued as much. Henry spoke of a similar situation of his daughter receiving a diagnosis quite late:

I think that's [late diagnosis] more common in girls apparently. It's harder to spot. (...) Other parents in similar situations, but especially with girls, they've all had quite a similar story.

It seemed that fathers found it helpful to their understanding of the situation to consider whether the things their child did were 'typical' Asperger's or different in some way.

Some of the fathers described Asperger's in terms of being a "hidden disability" (Peter). Peter spoke about the support that his son had received at University:

If he'd been in a wheelchair, that sort of disabled, whether that would have been more obvious that he needed support... I think there would have been more support because the disability is more visible. With Asperger's you just see someone walking around, you don't see what's going on in their little globe in their head, that's fuzzing around at a million to one times a second.

There was a sense of frustration from those fathers who talked about how AS and HFA are less visible 'disabilities', as they seemed to feel that this led to less support than their children might deserve.

5.3.2 Diagnosis: a road map or a bereavement?

Most of the fathers spoke of how they felt about the diagnosis of Asperger's or High Functioning Autism. Andrew was not at home when his son was diagnosed and did not appear to place much value either way on the diagnosis. The other fathers talked about the diagnosis either as a useful way of helping to understand their child, or as a very difficult event. Some fathers talked about the diagnosis both as difficult and helpful.

Sam spoke about the diagnosis as being a helpful way of understanding his son:

And she said yes, it's Asperger's. And of course from there on, I don't say it became easy, but it became easier, in as much as we'd got a road map, and we could see what had to be done.

This theme of the diagnosis helping parents understand what they needed to do to support their child and to understand some of their behaviours was present for most of the fathers. Some fathers also spoke about how it was helpful for their child. For example, Charles said of his daughter:

The diagnosis helped her. Suddenly she was freed of self-doubt, she understood.

Henry also spoke about this for his daughter. It seemed that an explanation of this sort helped them to understand themselves and why they might find some things difficult. The diagnosis was also viewed by some as a way to access more support. For example, Peter thought they might have missed out on some support by not knowing the diagnosis earlier:

We didn't access [some support] because we didn't know the full diagnosis early enough.

However, others were unsure whether an earlier diagnosis would have been helpful. Mike described how he felt they had avoided his daughter experiencing some stigma by receiving the diagnosis later:

So we kept from her (...) the fact that she was different to the point where there was something that could name her difference, which could make her feel second class.

Charles described the strongest negative reaction to the diagnosis. It seemed that he had difficulty in marrying the diagnosis with his expectations of who his daughter was:

I'd possibly describe it as the worst thing that's happened to me in my life so far. It was like a bereavement (...) because the daughter that I thought I had, had suddenly gone. The diagnosis took that away.

Henry also described some similar thoughts when talking about his daughter:

It changed when she had her diagnosis. Sometimes I look at, you know, these pictures, before she was [diagnosed] and I think, is that the same person?

From Charles and Henry there was a sense that they had certain expectations for their child's life and they experienced a sense of loss when these expectations had to change. The idea of unmet expectations was also present in Ben's story:

He was an absolutely delightful little boy, I thought life was going to be an oyster for him. He was so lively and boisterous and always laughing and, you know, just, just, Oh!...

Charles commented on how others did not seem able to understand the diagnosis as a bereavement to him, as they could not see that anything had changed. However, it seems that this could be quite a common experience for fathers.

Andrew compared his son Don to his other son frequently during the interview. There was a sense that Andrew was looking at the differences between his sons and thinking about how things might have been different for Don:

[Joey is] brilliant at maths, so that gives him (...) an interest but also means that he has value, so some people are quite happy to have him, and don't care that he's rather too obviously bright. Don is different. Because he's autistic.

5.3.3 Just having that knowledge makes a big difference.

A strong theme through all the interviews was of a developing understanding of the situation. Fathers started from different positions, either not knowing, or suspecting that something was different. For example, Ben spoke of not knowing that there was a "problem", but that other people knew. He also spoke of how "hindsight" gave a different perspective on events:

We didn't know what the matter was. Nobody told us there was a problem, but there was clearly a problem with the benefit of hindsight.

There was a clear sense of frustration from Ben that other people could have told them that there was a problem much earlier on. It seemed that Ben could not understand why they were not told when it was clear to others. Other fathers described being aware of a "problem", but being unsure what the reason was. Peter said:

We knew there was something odd going on, when he was [young], and my wife had been reading up.

There was a pattern of parents seeking knowledge about what was happening. Either "reading up" or seeking help from health services. Sam describes the process his wife went through:

Maria knew from the start there was a problem, but didn't know what the problem was, and went through all sorts of things with doctors diagnosing a whole variety of things.

Mike also spoke about seeking information:

We're literate, we've got quite a lot of books on the subject, so we can read, and I go to conferences.

Fathers spoke of this development of knowledge and understanding of ASC and how this relates to their child. They also spoke of developing an understanding of themselves and their reaction to their

children. This was a particularly strong theme for Charles and Henry. Charles spoke of developing an understanding of himself through Family Therapy:

That was the start of my recovery, (...) that guy helped me to understand why I was thinking the way I was thinking.

Alongside the development of understanding, fathers spoke of learning to approach things differently. Henry commented:

I've found that I've had to learn to try and accept those things a bit more and deal with them.

This acceptance seemed to come about when fathers could understand why their child might do things in a certain way, for example, Charles and Henry both spoke of coming to understand that they could not just ask their child to tidy their room, as there were many processes within this task that their child could find difficult.

Fathers were also concerned about the people around them not understanding their children. There was a theme across the interviews that in order to cope with their children or help them, other people need to develop their knowledge, understand the person and be able to pass on that knowledge to others. Andrew spoke of people misunderstanding his son:

And also a lot of people (...) a lot of times people have misunderstood what he's doing and turned nasty.

Ben talked about a crisis team worker who he perceived as not having the right knowledge to work with his son:

She was just so naïve and she just didn't even have an inkling of how to engage.

There was an expectation from most of the fathers that people working in support services should have an understanding of ASC and how they might need to adjust their practice. There was a sense of frustration when fathers did not feel that this knowledge was there.

Fathers in this study also spoke of how friends and family were able to cope better with their child if they understood them. Peter spoke of his sister-in-law:

And she gets on alright with Simon, can cope with him, she understands.

There seemed to be a link, for the fathers, between a better understanding and being better able to cope with the behaviours and difficulties of being with a person with AS or HFA.

Henry commented on how it is easier to talk about his difficulties and feelings if the person he is speaking to has some understanding of ASC:

Just having that knowledge makes a big difference. Because then you understand that actually, you know, a lot of things (...) are part of the condition.

It seems that Henry felt that people were less judgemental of him if they understood the impact ASC can have on the family and the difficulties of learning how to best manage things for their child.

Henry also spoke about how he and his wife have frequently looked at themselves and questioned themselves as a result of his daughter's diagnosis:

It's hard, cos people do look at themselves. I look at myself and think, ooh, is that where she gets it from? And Rita does as well, so yeh, that's quite a big thing that's happened really, is that looking at yourself.

This idea of looking at yourself seemed to be a part of Henry's way of trying to understand what was happening and looking for reasons and explanations of what had happened.

5.4 The intense emotional impact

Throughout the interviews the fathers commented on the emotions they felt in reaction to the difficulties and the good times. They also commented on some of the ways they have coped with these emotions. In addition, many fathers commented on other events that have affected their experiences over time, as well as how their children's mental health has affected things. This theme developed from four subthemes: 'Seeing my child suffer was testing and it was painful', 'The ability to provoke that intense emotion', 'Getting away from all the issues at home' and 'Those other events have shaped quite a lot that has happened'.

5.4.1 Seeing my child suffer was testing and it was painful

All of the fathers described times when they had seen their child struggle or suffer and there was a sense of how difficult they found this. Sam described how he felt when he took his son to calm down in his bedroom:

'[Stay there] until you're ready to re-join the family, otherwise we'll stay here all night'. But I just sat there. And that was testing, and it was painful.

There was a sense in a few of the fathers' experiences that the methods they used to help teach or calm their child were quite difficult for them to endure. For example, with Sam's role above, he needed to sit there whilst his child was very distressed, but with the knowledge that in the end it would help him calm down.

Peter, Henry and Charles described times when their child was hurting themselves, Peter said:

We've had times where he's been literally screaming and banging his head.

Charles described how he felt when his daughter started to self-harm by banging her head:

Which is really quite distressing when your child starts to do stuff like that.

The distress that the fathers felt, witnessing their child hurt themselves, seemed to stem from the inability to help their child in a way that might avoid them needing to self-harm. This can be seen in Henry's desires to help his daughter find ways to deal with the crises that have led her to overdose in the past:

I hope that she can lead a happy life. I have to be realistic, that she will have crisis points. My hope is that, however bad they get for her, she doesn't contemplate, have suicidal thoughts again.

[I] just hope that she learns to cope with those things.

In a few of the fathers' stories there was a sense that they found it distressing to think about other people causing their children to suffer, either deliberately or not. For example, Andrew described his son being bullied:

Children tormenting Don because he's different.

He described a series of events of Don being victimised, such as children throwing stones at the house and it was clear that he felt very angry about this, as well as very frustrated that other people could continue to do this. This past experience made Andrew worried about his son's vulnerability, as he thought Don "naïve" about what other people might do.

Henry described a less deliberate example of people upsetting his daughter, as she was excluded from a group that was set up for her friends to talk about some of the difficulties of being friends with her:

She was completely excluded. It wasn't a group that supported her, and it really, really upset her. All her friends she felt turned against her. (...) It was terrible.

Whenever the fathers spoke of these types of events, which had upset their children, or led them to struggle with a situation, they were communicating their anger, frustration and sadness that these things happened to their children.

5.4.2 The ability to provoke that intense emotion

Throughout the fathers' narratives there were examples of the strong emotions that were provoked by their children and by the situation. Henry spoke about his daughter:

There's the ability to provoke that intense emotion (...) and really is quite intense, but in good ways as well as in bad ways.

Peter also spoke about the good and the bad extremes of emotion he could feel towards his son. This was a repeated theme through all the interviews; the unconditional parental love against some strong feelings of anger or frustration:

I love him dearly, but I find him ever so frustrating. He drives me absolutely mad. (Peter)

Henry also spoke about how he felt when he had been very angry with his daughter as a teenager and had “slapped her round her shoulder⁵”:

It was awful. And I never ever thought I would be like that, I never thought I had that in me.

This frustrated, angry reaction to their children was echoed by most fathers. Andrew also spoke about how his feelings of frustration would cause him to behave in certain ways with his son:

Sometimes I just ended up by shouting at him, when he wouldn’t listen.

Charles described realising, with hindsight, that he had been experiencing extremely low mood after his daughter’s diagnosis:

I think I was depressed, now. I think I can understand and my wife I think certainly understood that I was depressed.

Charles was the only father to talk about becoming depressed in these terms, but there was a sense from other fathers’ stories that some people had experienced times of feeling that they were struggling with their mood. This seemed to be related partly with times that their children were experiencing their own mood difficulties, partly around coming to terms with the fact that their child has AS or HFA and partly at times when fathers have found it particularly hard to understand their child.

There seemed to be a sense of guilt from some parents about how they interacted with their child before they were aware of a diagnosis and how and when they went about seeking a diagnosis. These are impressions from the way fathers talked about certain things in the interviews, which are difficult to demonstrate with quotations.

All of the fathers talked about the worries they have for their children. Some parents talked about acute worries for the safety of their children in particular situations, such as when Ben’s son stopped calling him after a night of constant phone-calls:

⁵ Information around this comment was considered, in the context of the historical nature of this one-off, public incident, alongside Henry’s daughter’s current age, and this was not considered an incident in need of reporting for safeguarding.

That's when I really panicked, I thought he was into a coma or something.

All of the fathers described worries for the future of their children, particularly about how their child might cope when they are gone. Mike said:

How she would cope without us, that's a significant worry.

This seems to link in with the responsibility that fathers feel they hold for their child. It seemed to me to be a worry about there being no-one to keep their child safe. Some fathers expressed their worry that their child might harm themselves when they die. Peter talked about his son, who had told him that he would "just commit suicide" if Peter and his wife died:

As an adult, 22 years old, he's treated as an adult, he wouldn't be able to cope with life. So, we worry a lot about his future, if anything happened to either of us really.

It seems that Peter's son shares Peter's belief that he would not be able to cope without him. This may reflect Peter's 'rescuing' role for his son, as he is used to having someone there to come to his rescue in difficult situations. Henry spoke of a similar fear for his daughter in the future:

My fear is that she will kill herself. Cos that's what she's tried to do before.

This was not such a direct causal relationship as seemed the case for Peter, but Henry did seem to feel that he is filling a role of helping to keep his daughter from crisis.

Sam also spoke about his worry for his son's mood in the future:

There is an overlaying sadness there which is potentially [a] worry, very worrying indeed.

5.4.3 Getting away from all the issues at home

When the fathers spoke about the way they reacted to the strong emotions and struggles at home, the majority spoke of ways of escaping and avoiding the feelings and the difficulties. Charles spoke about how he coped around the time of his daughter's diagnosis, when he was struggling with his emotions:

And the way that I dealt with that, probably in common with most men, was by separating myself from the problem. (...) I bought myself a big motorbike and drove off, you know, to relax, to get out of the situation that I was in.

Others spoke about how work was a good way of escaping the home and the difficulties there. Peter spoke about his work:

This place is my get out clause. I wouldn't be able to be at home with him all the time.

Ben talked about getting away after a particularly stressful incident with his son:

Well we were absolutely shattered, and we went off for a week on holiday, we just said we didn't care where we went, what it cost, we were just going. Don't care, just out of here.

Some fathers spoke of these physical escapes such as work and holidays. Some talked about how they didn't think about the difficulties. When asked about the impact of being a father of someone with Asperger's on his relationships, Sam spoke about how he didn't even think about how things might have been different and couldn't make sense of some of the questions I asked about the impact on his relationships. There was a strong sense that Sam avoided thinking about how his life might have been different if his son had not had AS:

Yes of course life would have been different, but it, you know, it's not worth thinking about.

Henry spoke about the difficulties he has if he has too much time to think about what is happening at challenging times. It seems that he prefers the distraction of having to undertake practical tasks:

When you're there and dealing with things, and this is what I've found in the past as well, you can sort of cope a little bit better. But when you're home and thinking about things, then it's harder.

5.4.4 Those other events have shaped quite a lot that has happened

During the interviews all the fathers also spoke about how other events and situations in their lives impacted on their experience of parenting. For the fathers of the adults who had also been diagnosed with a mental health difficulty, the mental health difficulty featured strongly in their descriptions of their experiences.

Some of the fathers had experienced the deaths of close family members in the last few years. These bereavements often bring their own difficult feelings, but also on a practical level can affect the time you have to deal with things. For example, Charles said:

My father just died in October as well, so, when we thought we were going to have a little more time to ourselves, suddenly we're into this probate situation.

Henry spoke about how the deaths of some family members happened at the same time as his daughter's first overdose. He spoke about how it was difficult to deal with any of this at the time and that all the events can end up tied in with one another:

In a way all of those events have shaped quite a lot that has happened subsequently, you know, because it was quite a traumatic time.

Some of the fathers and their partners experienced physical health problems as their children grew up. Peter spoke more about how this might have impacted on his son, as he and his wife had found it difficult to be a parent in the same way following health difficulties. Speaking of his son he said:

In a way he's been through quite a traumatic life.

Sam spoke about how his son Simon's difficulties, who experiences psychosis, overshadowed any of Mark's difficulties:

I've been coloured the whole time by Simon's problems almost more than Mark's really. Mark's problems are nothing compared with Simon's.

For the parents whose children had been diagnosed with a mental health difficulty, or who were worried about this happening, the effects of the low mood or anxiety were spoken about throughout the interviews. For example, Henry spoke about the time following his daughter's first overdose:

I went through a period, probably a year or so ago, I kept having lots of nightmares about all three of my children, in different nightmares, dying at some point, because of what had happened.

Ben spoke about how he had developed a different understanding of his son's behaviour over time. It seemed that this different understanding and acceptance affected how he felt about his son and his behaviour:

I've come round to recognising now that it's a sickness, which I refused to do really before. Now I just accept, I don't say it to anybody, but I accept he's ill.

It was unclear whether Ben was speaking about his son's mental health difficulties or his diagnosis of ASC, but the impression was that he was talking about both. Within this idea, was the realisation of the life-long nature of his son's difficulties, which was something which all of the fathers spoke about. There was also the knowledge that their child might face further difficulties in the future. For example, Mike talked about his worry that his daughter might develop depression in the future:

So the worry, the big worry is that [anxiety] tips over into depression. So I work really hard, that's why I work really hard on it when she gets like that.

Mike seems to feel a pressure to ensure that his daughter does not develop depression and that it is his role to "keep her on an even keel" as far as possible. This links with the ideas of responsibility and of the difficulties of seeing your child suffer.

5.5 The importance of good support

The theme of 'the importance of good support' arose in the interviews with all of the fathers. Fathers were asked as part of the interview about their experiences of accessing support for themselves and

their child. Fathers spoke of their experiences of support services, such as Social services or NHS services throughout the interviews and not just in response to the specific questions around accessing support. Fathers also spoke of the support of family or friends and many considered the experiences of other parents. The sense that came out for me during the analysis was that when support from services, family or friends was good then life became easier and people felt stronger working together. When people perceived support to have been lacking or where they had to fight for the support, there was a sense of those fathers and their families being left in a vulnerable position and feeling unsafe. The theme was comprised of three subthemes: 'Perpetually badgering for support', 'With support life can flourish, but we've had nothing' and 'Maintenance or collapse of exterior world'.

5.5.1 Perpetually badgering for support

All of the fathers spoke about seeking help and support from services. Fathers spoke about seeking support in understanding what was happening for their child, such as Peter, who described it as fortunate that they were referred to CAMHS:

Fortunately one day, we managed to get (...) one of the Doctors in a good mood, and they referred us to the family clinic.

There was often a sense that when people were seeking support, they needed to be lucky in order to be sent to the right place, or else they needed to be "pushy". Henry described his experience of trying to get the support he wanted for his daughter:

They never picked up on those things, and it was only cos we were quite pushy I suppose, and said, look she needs to be seen by a psychiatric doctor.

This was an experience that Charles also commented on:

We had to push all the time, when we got no for an answer, we had to find some alternative ways around that. Eventually I suspect, just because we were a pain in the butt, eventually we got what we needed. But it was not easy, it was not easy.

There was sense of frustration from the fathers that spoke about getting lucky or having to push for support and that the support was not just offered without them having to fight for it. Mike spoke about a feeling that he was not pushy enough with services when his daughter was younger:

We didn't force it through, we didn't follow it through hard enough, to get her diagnosed at a younger age.

Mike did not necessarily see this as a bad thing, as he spoke of his family as being fairly well supported without this diagnosis and he felt some stigma might have accompanied the diagnosis.

Ben spoke of the effort he felt he had to put into trying to find support for his son:

Over the last few years I've tried, just bent over backwards to try and get him help, to try and find him pathways and all the rest.

Ben came across as angry that these pathways had not appeared and that his son remained unsupported. It is, perhaps, a result of it often being more difficult to diagnose ASC in more able people and a difficulty of mainstream services understanding how to support a person once they have a diagnosis that has led to difficulties such as Ben describes.

Often where support had been agreed fathers commented that they needed to keep fighting to ensure that the support was being delivered as planned. Charles spoke about his experience with his daughter's school:

We were perpetually badgering the school. Finding out, how's this going, what's happening, why's she not getting support, what's going on?

Sam spoke about his fight to keep support for his son when the council tried to take away his statement in order to send his son to a mainstream school in the county:

Someone said, 'no, no, he shouldn't be statemented', and that's what the pink file is all about. The arguments that went on over the months with the council etc. etc.

Sam expressed anger that someone could simply decide that his son did not need a certain level of support and he appeared proud of how they had challenged this decision in order to attain the support they wanted for their son.

Some of the fathers spoke about having to go to private health professionals in order to gain answers about their child or support for themselves. Charles spoke about going to a private child psychiatrist for a diagnosis:

We paid, we went to a private child psychiatrist, cost 1500 pounds, and that was the key that unlocked the flood gates, without that diagnosis, we would have got nothing.

Charles also spoke about going to see some private counsellors and Ben spoke about using a private consultant for support in understanding his son when things are difficult. Henry said that he would pay for therapy for his daughter, if she would go.

Mike was the only father who commented that he had not sought any support for himself or his family:

Never sought support for ourselves, for the family as a whole, and I can't think of any instance where, looking back, I would have thought we should have done either.

Mike appeared to be the most satisfied with the overall support that his daughter received from social services, which kept her very well supported at work and personally. This good support already in place may have led to him feeling no need to seek further support.

5.5.2 With support life can flourish, but we've had nothing

All of the fathers spoke in some way of feeling let down by the services that they tried to access. There was a sense that these feelings of being let down led to fathers and the families feeling angry, out of control and somewhat abandoned. This theme of feeling let down came across very strongly in Ben's account:

No one comes, no one, nothing, we've had nothing, we've had nothing.

Ben spoke of several instances through his son's childhood and into adulthood, where the services had not helped in any way. For example, where school had not told them of his son's difficulties, where mental health and crisis services have not engaged or have passed on responsibility and where Ben's son has been discharged from hospital with no support.

Most fathers spoke about how their children's schools, at some stage, had not coped well with their children. Peter said:

The junior infant school, couldn't cope with him, didn't know what to do with him.

Mike spoke about his daughter's "go getting primary school":

Even from reception class they were really pushing them. So she found herself in the 'I can't be bothered with you, I'm going to focus on the ones that are doing well, category'. So she was in the bottom group and she wasn't focused on.

There was a strong sense of people feeling let down by a lack of communication from the schools their children went to. This can be seen in Ben's comments that "nobody told us" and in Henry's comments on how the secondary school handled communicating about his daughter's behaviour:

The school hadn't contacted me or anything, they did actually do it really badly, which they realised afterwards.

This lack of appropriate communication led to a very difficult situation for Henry. This was a common theme across interviews, as a perceived lack of support and communication left fathers in an uncertain place. It seemed that if the fathers felt let down by a service, they either chose to fight for support or they tried to continue without anything, until something else might be offered. Sam spoke about the

social care team who were supposed to be helping find his son an independent living placement over a number of years:

And they've been absolutely useless, completely and utterly useless, until now, and, mainly because no one ever stayed on the case long enough.

Some of the fathers spoke about where they laid the blame for feeling that they had been let down by services. Some fathers spoke about particular professionals letting them down, as Ben felt about the Psychiatrists that he has encountered and several fathers felt about the Psychologists and Doctors who initially did not diagnose an ASC. Some fathers thought that the inconsistency of staff was partly to blame, as with Sam in the above comment. A few fathers also saw it as a larger issue of the resources that the services were being given. Henry talked about how his daughter had not received adequate support after leaving children's mental health services:

I think it's poor. But I don't think it's the profession itself, I think it's the complete lack of funding.

Charles also spoke about his worries that the CAMHS in his area had to reduce their services, as he really valued the support he had received:

They just don't have the funds to do what they need to do. It's just crazy, because I would probably say that my wife and I would be divorced if it wasn't for their help.

Though there were many stories of feeling let down, each father also spoke about times that support services had delivered excellent support, Sam described these as the "glimpses of light". Some fathers had some good experiences of their children's schools, for example, Andrew was pleased with the preparation the school did in advance of his son transferring and the training that his teacher undertook:

The schools have been extremely good, impressively good, and they've gone out of their way to help.

Peter talked about how, though his son's school could not provide constant support, the support he did receive helped at other times:

Cos he had support sometimes, he could cope with the times he didn't have support.

Charles also commented about the school his daughter went to for A-levels and the support that her university were providing:

With support her academic stuff is [good], life can flourish.

Henry and Mike spoke about how having a consistent person supporting them has been helpful for their daughters. Mike spoke about how his daughter has had the same social worker transfer from child to adult services:

We have very good access to social services. There's one person who's been there the whole time for her. So I would say we're lucky in our borough.

Henry talked about the nurse who supported his daughter in CAMHS:

CAMHS were excellent, her nurse, she had a paediatric psychiatric nurse who was excellent, who stayed with her longer than she probably should. Not should have done, cos she needed to.

Henry and Mike seemed to view themselves as fortunate to have had this consistency, as consistency does not seem to be the normal case.

Charles spoke strongly about the positive effect that Family Therapy with CAMHS had on him and his relationships with his family, he spoke about how it "saved" him, as his relationships with his wife and daughter were in "jeopardy":

We saw a family relationship therapist at CAMH, it was the most life transforming experience I think I've had. And I wonder what I would have done without that actually.

All of the fathers spoke about the support they received from their partners, children and family. A theme developed of the fathers experiencing tensions in their relationships where they had different views to the people around them and feeling that being together and supportive brought strength. Charles' experiences strongly represented these ideas, particularly around the tensions of difference. He spoke about feeling very separate from his wife and his daughter, as he viewed things differently to them:

... when I tried to interact with my daughter, there was tension, there were tensions there.

Peter spoke about how he had felt close to his own father, as they had shared interests since he was "knee high to a grasshopper", but that he was disappointed that his son was not interested in joining him on his practical projects:

[I] get a bit upset sometimes, cos he doesn't have the interests that I have.

Some of the fathers spoke about how they felt some strain in their relationships with their wives when there was a disagreement about how to deal with something relating to their children. Andrew spoke about this:

Kate doesn't like that, still didn't think I ought to shout at him. We've disagreed on how we ought to deal with him. (...) It has strained the relationship at times.

Most fathers spoke about the support they received from their partner in coping with difficulties. Sam talked about his relationship with his wife:

I don't want to imply that we were rifted, cos we weren't and we used to sit in the dark at night and say, well I'd say this to her: 'I couldn't get through this without you'.

Ben and Charles both spoke of a healing of their relationships with their wives. Ben commented about how his relationship has improved, whilst still being a work in progress:

Our relationship's got a lot better recently. At least we've resigned ourselves to make it so.

Charles spoke about how he and his wife had to "apply a good chunk of forgiveness" in the process of healing their relationship, with the support of Family Therapy. He commented on how his relationship is now:

I would say the relationship with my wife is now really, really good. We are certainly stronger for it, we're partners now, in a way that we were almost adversaries before.

Mike talked about how his family needed to act together to support each other, rather than Mike seeing things as having an individual impact on just him:

It's the family that is affected, and I'm part of the family, cos we're a close family. So it's the way we all deal with Angela that matters.

Most of the fathers compared themselves to other parents in similar situations during the interviews. Some were very curious about how other fathers had answered during the research and Charles in particular was eager to give some advice to other fathers of people with AS or HFA. There was a sense that fathers either thought of other parents as being in very different positions to themselves, or felt a sense of community in thinking of other fathers in similar situations.

Some of the fathers considered themselves to be in a fortunate position compared to others. For example, Mike spoke about the difficulty of having a child who is "more severely autistic":

So it's never been an issue as you might have with someone who's perhaps more severely autistic, where their behaviour can be such that it really does make life difficult.

Ben also spoke about feeling in a different place from other parents at a parent support group:

We're not like these people, we're away, we're on the road.

However, he also spoke about a developing feeling that he might have more in common with these parents as his son's mood and engagement has dropped:

You know, I'm beginning to recognise where the other people at the parents suppers are [at].

Charles wanted to give advice to other fathers of people with AS or HFA, based on his experiences of what he has found helpful:

I would be keen to just get the message out to other men who are in the same position that you can't just go out on your own, on motorbikes or runs round forests, you need to talk about this stuff.

5.5.3 Maintenance or collapse of exterior world

The fathers had different experiences of how their social lives and support networks had been affected by being the father of a person with AS or HFA. Some of the fathers reported that there had been no impact on their friendships, or that it had only increased their networks. The other fathers reported some difficulties in their networks.

Ben, Sam and Mike reported that there was no impact on their relationships with friends. For Ben this seemed to be as a result of him not really talking about his son within his friendship group. Sam seemed to attribute his maintenance of friendships, in part, to his friends' understanding:

I'm very content with the friends I've got and we have a great time, and they're very understanding.

Mike felt that his daughter was a "positive asset" to meeting people and having friends. He talked about the people they meet:

People are always very sympathetic. Angela's lovely, I mean, everyone that meets her, she brightens up their lives.

Henry reported a mixed response from his friends, as some were supportive, but he felt that some were very judgemental:

Lots of people were very supportive (...) some of my friends weren't supportive. The sort of things they said, really did (...) cut deep.

Peter, Andrew and Charles spoke about their social lives disappearing since the birth of their children and the subsequent difficulties. Charles described how his outside networks "collapsed" and it seemed that this was an isolation instigated by himself, partly through his low mood and partly through the other responsibilities that now occupy his time:

I would say my exterior world kind of collapsed. The compass came in, the boundaries came in. I was no longer operating in as large an orbit.

Andrew also described restrictions on his social life. Again, this seemed to be partly because he had other responsibilities, but there also seemed to be a sense of shame around Don's behaviour, which he didn't want others to see:

When Don was a child it was very difficult to entertain, so social life was reduced and we couldn't really invite people round because Don's behaviour would spoil it.

There is one friend I haven't visited since, cos I'm not prepared to take Don there when he's going to upset people.

Peter partly attributed the "pulling away" of other people to his son, as he finds it difficult to meet new people. He also attributed it to other people finding it difficult to cope with his son. He spoke about some of his extended family:

It's not easy with family understanding him. And if they don't understand him, they tend to sort of pull away. They don't want to upset us, so, rather than try and find out how to get on his wavelength (...) they find it easier to pull away and not be involved (...) we end up quite insular, just the three of us.

Henry spoke about trying to develop new networks, and the difficulty of this as a father who took on the caring role and having less opportunities than a mother might have:

Not the only dad in the playground, but socially when you're at home, being a dad, it's harder.

Henry seemed to view this as a gender difference, as mothers might be able to go around another mother's house more easily than he can as a man.

Some of the fathers spoke of how they found their work colleagues supportive. Ben spoke of how he did not talk with his friends about his son, but his work colleagues were very familiar with him, as he had gone to work with Ben as he was growing up:

He used to come to work at my place, and all that, and they've been very engaged with the process of his schooling and everything else.

Henry also spoke about how he found his work colleagues supportive and "non-judgemental" when things were difficult at home:

Working has been really useful and comforting and this is part of the environment as well. Because, you know, I guess you do work with people who are a bit more open-minded in that respect.

6. DISCUSSION

In this section I will summarise the results of the Interpretative Phenomenological Analysis and discuss how these results relate to the existing research literature. I will also consider how these results are clinically relevant to our work with fathers and families of children and adults with AS or HFA. I will discuss the contribution of this study to the research literature and the strengths and limitations of this study, as well as my recommendations for further research in this area. I will end by discussing what I have learned both professionally and personally from this research process.

6.1 What are the experiences of fathers of adults diagnosed with AS or HFA?

The Interpretative Phenomenological Analysis of the interviews with seven fathers of adults with AS or HFA produced four super-ordinate themes describing the fathers' experiences:

- The changing role but constant responsibility of being a 'Father'
- The importance of knowledge and understanding
- The intense emotional impact
- The importance of good support.

6.2 The changing role but constant responsibility of being a 'Father'

The first theme: 'The changing role but constant responsibility of being a 'Father'' described the participants' perceptions of their responsibility to care for and protect their child, doing "whatever is necessary" to support them. Some fathers spoke of trying to make their adult child independent and others of protecting and rescuing them from difficulties. The fathers spoke of how their role had changed as things have changed for them and their adult child. Some fathers felt that there had been an overall pattern of progress over time, whilst others spoke more about constant ups and downs. There were comments through most of the fathers' interviews about the roles of men and women and how things might be different for fathers compared to mothers.

Fathers described their role changing over time, which was an experience also shared in O'Neill's (2013) narrative study of parents of adults with AS or HFA and Golden's (2012) phenomenological exploration of caregivers of young adults with ASC. Golden's (2012) theme of "Change" also reflected the awareness that they would remain in a caregiver role for their children throughout their lives, which is an awareness that the fathers in this study shared and extended into a responsibility to ensure support after their own deaths. There were also some differences with Golden's (2012) themes, as none of the fathers in this study described their relationships as "non-reciprocal", or spoke about unusual bonding. However, relationships were the focus of Golden's (2012) study, so it is likely that these areas were explored in more detail with the caregivers than was the case in this study. The

fathers in this study did describe differing relationships with their children, but in general talked about “meaningfully interacting and communicating” as described by Donaldson, Elder, Self and Christie (2011).

The fathers in this study also described some of the roles that they took in their son or daughter’s lives. These roles mostly fit with those described by Vacca (2013) as the roles anticipated by fathers before the birth of their child, such as provider, caregiver and teacher. Woodgate, Ateah and Secco (2008) also spoke of the “vigilant” parenting style of parents of children with autism. This vigilant parenting included trying to anticipate the next step in their child’s care and doing whatever is necessary for their child. These experiences were also described by most of the fathers in this study. The fathers in this study also described roles similar to Axup’s (2012) description of the “guardian and protector” (p.113).

6.2.1 Clinical Implications

Knowledge that fathers experience this sense of responsibility and the feeling that they would do whatever is necessary to support their child suggests high motivation for them to become involved with any support offered to their children. Walters, Tasker and Bichard (2001) interviewed fathers of children involved with their service and examined what factors made it more or less likely that a father would attend sessions. They suggest that: “taking a special interest in the father and his history and, in a clinic session, positively connoting his role, is likely to be very important” (p.17). They also comment that clinicians should look beyond the assumptions that fathers may be too busy at work to attend and “attempt to work on making fathers feel their role is far from peripheral” (p.18).

The stories of progress and change experienced by the participants could be potentially supportive for other fathers and families. A service I have worked in uses ‘Messages of hope’ with families of children with ASC, to pass on stories of hope and progress from families at the end of intervention to those just entering the service. These messages of hope are based in the Narrative model (White and Epston, 1990).

6.3 The importance of knowledge and understanding

The second theme: ‘The importance of knowledge and understanding’ described the knowledge and understanding of fathers and others around them. Participants spoke about the different perceptions that they have of their child, such as seeing them as ‘different’ and talking about their child’s strengths, as well as how other people seem to view their child. Fathers also spoke about their view of the diagnosis of AS or HFA and whether this was helpful in giving them a direction of how to help their child, or if it was experienced as a loss and a bereavement. All of the fathers in this study spoke about

their developing knowledge of ASC and developing an understanding of their child. This development of understanding helped fathers to develop different approaches with their child and improved relations for most of the fathers. Fathers also spoke about how other people needed to have the right understanding in order to be able to cope with their child.

Fathers in this study spoke of the different perceptions of their child, including the difficulties of AS or HFA being hidden and misunderstood. Griffith, Totsika, Nash, Jones and Hastings (2012) found a theme of “He doesn’t look disabled” in their interviews with parents of middle-aged adults with AS, whilst Hoogsteen and Woodgate (2013) commented on parents having to explain that “he’s not the Rainman”. Lasser and Corley (2008) also talked about the “hidden nature” of AS making it difficult to explain the challenges that parents were facing. Portway and Johnstone (2005) discuss the risks of AS as a “non-obvious disability”, which can lead to misunderstandings and vulnerability for people with AS. Lasser and Corley (2008) also spoke about the parents trying to construct a “normal” for themselves. In this study the fathers spoke about their children being “Typical Asperger’s”, which seemed to be a way of constructing their children as ‘normal’ AS.

Many studies have talked about the reaction of parents to the diagnosis of AS or HFA. Fathers in this study spoke of the diagnosis being helpful, or as being a bereavement, which was also found in Donaldson, Elder, Self and Christie’s (2011) study with fathers. Donaldson et al. (2011) reported a theme of “Accepting the diagnosis” where fathers spoke of both relief in having knowledge of what was happening and a loss of the expectations they had for their child. Ryan and Salisbury (2012) spoke about parents in their study having difficulties in adjusting their view of the child and Altieri and Von Kluge (2009) reported that parents spoke about feeling devastated when they found out the diagnosis. York (2012) and Keller, Ramisch and Carolan (2014) both spoke about a process of coming to terms with the diagnosis.

Fathers in this study spoke about how their understanding and knowledge developed over time and how it was very important to have the right knowledge. O’Halloran, Sweeney and Doody (2013) talked about the fathers they interviewed going through a similar process of a “journey from awareness to diagnosis”, whilst York (2012) spoke of this in their theme of “regaining our balance”. Fathers spoke about the importance of other people understanding their child, which was also reported by Jones and Passey (2005).

6.3.1 Clinical Implications

Fathers spoke about their child appearing normal or less challenging with other people and only being able to understand the full impact when living with them. Professionals working with fathers of people

with AS or HFA should bear this in mind in assessing the child and family, listening to the parents' description of the challenges, alongside the presentation of the client at appointments. All of the fathers spoke of some of the strengths of their child, which is a story that is often not focused on in professional contexts. Professionals should build a picture of the strengths of the child in their assessments, alongside the challenges.

Fathers spoke about different reactions to receiving the diagnosis of AS or HFA. Some spoke of an extreme feeling of bereavement or loss and difficulties in adjusting expectations and perceptions of their child. It can be that diagnosis takes place in relative isolation from services that may be able to support fathers who are struggling post diagnosis. Signposting and information packs are often given to parents, but these may be difficult to understand and utilise at this overwhelming time. It could be advantageous to borrow a model that is often used in Memory Assessment Services, where families are directed to a liaison from the Alzheimer's Society, present in the building, after receiving a diagnosis of dementia (Jolley, Benbow and Grizzell, 2006). Similarly organisations such as The National Autistic Society or parent support groups could aim to have representatives present at diagnostic clinics.

Improving their understanding of their son or daughter was very important to all the fathers. They spoke about how understanding their child better through greater knowledge of autism improved their relationships with their child and their spouse. This highlights the need for providing signposting towards information and opportunities to speak to others in similar situations. Professionals working with parents of people with AS or HFA may find it helpful to ask about their understanding and to facilitate further development of understanding of how the child might experience life. Flippin and Crais (2011) talk about taking account of the differing learning styles of fathers compared to mothers and recommend: "learning strategies such as peer feedback, task oriented learning, and perhaps even friendly competition in our father training" (p.44).

6.4 The intense emotional impact

The third theme: 'The intense emotional impact' described how parents emotionally reacted to their children and the challenges of parenting someone with AS or HFA. Fathers described the difficulties of seeing their child struggle or suffer and how they often felt powerless to help them. All of the fathers spoke about their children provoking intense emotions, both positive, such as pride and love and more negative, such as anger and worry. Most of the fathers spoke about how they had coped when things were challenging and most spoke of either a physical avoidance, such as leaving the house, or a mental avoidance, such as trying not to think about the difficulties. None of the fathers spoke only about their adult child with AS or HFA but instead other events in their lives were included in their descriptions of

their experiences, such as bereavements, job changes, health issues and difficulties for their other children. Three of the fathers spoke about how their child's mental health difficulties also impacted on their lives.

The fathers described times when they had difficulties with their mood, often when facing challenges in relation to their son or daughter. The times they described as most difficult seem to fit with Barker et al.'s (2011) findings about the wellbeing of mothers of adolescents and adults with ASC, where they measured wellbeing using symptoms of depression and anxiety. The mothers in their study reported lower wellbeing when there were more behavioural challenges, when their support network was smaller and when other stressful life events occurred, in common with the fathers' descriptions of their experiences in this study.

Sivberg (2002) and Pottie and Ingram (2008) all spoke about the avoidant and distancing coping styles of the parents in their studies. As Sivberg (2002) described, fathers in this study also seemed to have developed these coping styles in reaction to the challenges of parenting a child with AS or HFA. Pottie and Ingram (2008) reported that decreases in positive mood were associated with escape and withdrawal coping.

It is interesting that the fathers spoke about avoidant coping styles, considering that participants were recruited through parental support groups, which could be considered quite an adaptive way of coping, though most fathers did not speak of active involvement in these groups. Clifford and Minnes (2013) surveyed one hundred and forty nine parents, only six of whom were fathers, about their coping styles and use of parent support groups and found that current support group users reported using more adaptive coping methods than parents who were past users of support groups and parents who had never accessed support groups.

The fathers I interviewed in this study also spoke about the direct impact of the challenges on themselves and on their child and families. This is in contrast to Gray (2003) who reported that fathers said that they were only affected indirectly by the impact of severe difficulties on the mother. Fathers in Gray's (2003) study also reported that there was little impact on their working life and fathers saw their work as a way of coping with difficulties, which was also reported by the fathers in this study.

All of the fathers expressed worry over the future of their child when they die and for their child's ability to look after themselves. Griffith, Totsika, Nash, Jones and Hastings (2012) and Donaldson, Elder, Self and Christie (2011) also reported that the parents they interviewed had these worries and hopes for the future of their children.

6.4.1 Clinical Implications

Fathers reported a range of intense emotions in reaction to some of the challenges of parenting their child with AS or HFA. One father described developing depression after the diagnosis of his daughter and others described low mood and anxiety. This highlights the need for professionals to be aware of the mood of the father. This may be difficult, as fathers are not always as involved with professional support, but could be checked with other members of the family. Fathers need to be made aware of possible sources of support with their mood, or involved in family interventions where possible. One of the fathers in this study, Charles, highlighted the “life transforming” nature of the Family Therapy that he and his family received. Most fathers described avoidant coping styles, which are often successful in the short term, but which can be detrimental to mood and relationships. Barker et al. (2011) comment on the benefits to wellbeing of social support and adaptive coping styles (Bridges, 2003; Cohen, 2004, cited in Barker et al., 2011). ‘Charles’ was eager to pass on the message to other fathers that talking to someone was the most helpful method of managing his mood and improving his relationships.

6.5 The importance of good support

The fourth theme; ‘The importance of good support’ described the fathers’ experiences of support from services and support from people around them. Fathers spoke about the difficulties of seeking and getting support and having to keep fighting to ensure that their child was receiving the right support. Fathers spoke about feeling let down by services when they failed to deliver the support that fathers felt their children and the family needed, either placing the responsibility for this on professionals or on a lack of resources for these services. Fathers also spoke about the times when support services helped them and their families and how this supported their life to ‘flourish’. They also spoke about the good support they had from their wives, families and friends. Some of the fathers spoke about how they had maintained or built their social support network since the birth of their child, but others spoke about how their outside world had ‘collapsed’, either through other people withdrawing or through more of a self-imposed isolation.

All of the fathers spoke about the impact of their experiences with support services. This was something that was also found by O’Neill (2013) in her theme: “The making, breaking, yet ongoing and painstaking relationships with services” and O’Halloran, Sweeney and Doody (2013) in their theme: “The impact of services”. Axup (2012) also described the experiences fathers had with schools and professionals, which were both positive and negative. Woodgate, Ateah and Secco (2008) and Hoogsteen and Woodgate (2013) spoke about the parents’ experiences of having to fight for support and parents feeling that they were on their own. Jones and Passey (2005) also found that parents of

children with developmental disabilities reported difficulties in gaining access to services and that parents reported the need to persevere with support services. Griffith, Totsika, Nash, Jones and Hastings (2012) reported that the parents they interviewed were surprised to be asked about seeking support for themselves. The fathers in this study did not seem surprised to be asked, even if they had not sought any support for themselves. This might suggest that the fathers that I spoke to were more familiar with thinking that fathers might be in need of support.

Fathers spoke about the support they received within their marriage and also the times that they felt separate from their wives. Some people reported that challenges had strained their marriage, whilst others reported that they felt they were closer, which supports Blair, Black, Chambliss, Hobbs and Urgarte's (1996) findings that stress had different impacts on the marriages of the parents interviewed. Brobst, Clopton and Hendrick (2009) reported that in comparison to parent couples of children without developmental disorders, parents of children with ASC experienced lower relationship satisfaction, but there was no difference in perceived spousal support, respect and commitment for their partners. Keller, Ramisch and Carolan (2014) reported that fathers felt isolated within their marriages and from others and Sivberg (2002) reported that parents of children with ASC scored low on measures of social support.

6.5.1 Clinical Implications

Most of the fathers spoke about having to fight for support and feeling let down by support services. In several cases it seemed that better communication from the support service could have avoided some of the difficulties experienced by the fathers. Examples of this would be for schools to keep regular contact about any difficulties and for services to ensure that parents are directed to a service that can provide support if their own is unable to accept them.

Fathers seemed to consider that the support they received was 'good' if it was in line with their own understanding of the situation, if it developed their own understanding, or kept their child safe. Fathers appeared to feel let-down by services where there was no support offered, or if their understanding was too different from that of the support service. There is a balancing act that needs to be undertaken in services, in considering whether to align with the fathers' understanding, or whether to aim to develop a different, shared understanding, such as took place for Charles through Family Therapy.

Some of the fathers spoke about the collapse of their social networks, partly due to the challenges of socialising with their child, other people withdrawing and the time and energy needed to maintain friendships. Fathers who find themselves without family or social support could be encouraged to

access support groups and also to make use of the online networking opportunities available. As Heiman and Berger (2008) recommend, there is a: “need for effective programs of intervention for parental support, (...) to help parents (...) to develop and employ more adequate coping behaviours and to enable parents to better meet both their own needs and those of their children” (p.297).

Some fathers spoke about friends and family withdrawing through a lack of understanding, so it might be useful for professionals to develop resources or signpost towards existing resources that help other members of family and friends to understand ASC.

It was apparent from the experiences of the fathers that they and their families were looking for different support at different times in their journey. Therefore, professionals working with these families will need to collaboratively tailor the support that is offered to each person dependent on their current needs. ‘One size fits all’ programmes of support are unlikely to provide the support that people will need at the correct time. Meadan, Halle and Ebata (2010) suggest that the type of support required may depend on the age of the child with ASC and times of transition, such as school changes and developmental stages.

6.6 Contribution of this study

This study provides information about experiences in at least three under-represented areas. First, the key area of examination was the experience of fathers of people with a diagnosis of AS or HFA. As past research has tended to focus on the experiences of mothers or ‘parents’, with an under-representation of fathers (Braunstein, Peniston, Perelman and Cassano, 2013).

Secondly, this study explored the experiences of fathers of adults, whilst the majority of research which was reviewed was about parents of children (under 18 years old). Exploring the experiences of fathers of adults provides information about parenting in those transition periods of adolescence and becoming an adult, as well as the experiences of older parents.

Thirdly, the fathers included in this study were fathers of both daughters and sons. DePape and Lindsay (2014) commented that most of the studies included in their review of thirty-one studies, did not include parents of daughters. This is therefore another important area in which to build our knowledge, in order to better understand the experiences of this group.

The themes identified from the interviews highlight several implications for the clinical practice of people working with fathers and families of people with AS or HFA. They also raise some ideas, which were articulated by some of the fathers, of the value that is placed upon fathers compared to mothers. This study helps to show the need for a better understanding of fathers and that consideration is needed around the idea that “mothers are more interesting”.

6.6.1 How are the experiences of these fathers different?

The question could be asked as to whether the results would be any different for any other father of any child? The examples given by the fathers in their interviews would suggest that some of the experiences might be common to most fathers, but with a sense that the frequency and intensity of situations are different for this group. One of the experiences that might be common to most fathers includes feeling responsible for your child and worrying about their future, however for most fathers there would not be the same worry about the son or daughter's ability to care for themselves, or the worry that the child might commit suicide. Similarly, most fathers would find it distressing to see their child suffer or struggle, but the struggles are likely to be more frequent for people with AS or HFA than people who are 'neuro-typical', as many aspects of day to day life can be difficult and distressing for them.

For me, it is helpful to consider the aspects that are different for a person with AS or HFA compared to a 'neuro-typical' child, as this can help with the context of the experiences that the fathers were describing.

As discussed earlier, ASC can be considered as a different style of thinking that leads to different ways of behaving. People with ASC often have difficulties with understanding verbal communication and social situations. This may be very difficult for people around them, particularly where individuals with AS or HFA have developed strategies to make it appear that they are understanding what is being said and what they are expected to do (Attwood, 2007). Children and adults with ASC may also not place the same significance and importance on things as their parents might, for example, understanding why their personal hygiene is important to their parents. People with ASC can be quite direct in saying what they think, as they may not be aware of the social rules around what you can say to someone else and this apparent bluntness can be quite difficult for people around them.

People with ASC tend to be quite rigid in their thinking and like to stick to familiar routines. This can be difficult for the people around them when there is a need for a change in some way. Parents may try and push the limits in bringing their child's routine into line with their own needs and it can become quite anxiety provoking and frustrating when they reach the limits of flexibility. This might be particularly apparent at the times when parents are trying to help their child through a necessary transition, or when trying to teach the skills of independence and when parents can see a risk to their child's safety, as the resistance to change may leave them feeling quite powerless.

6.7 Strengths and limitations

An important strength of this study is its contribution towards the very under-researched area of the experiences of the fathers of adults with AS or HFA.

This study included seven fathers of adults with AS or HFA. This is within the recommended sample size for IPA studies at this level (Smith, Flowers and Larkin, 2009). However, it is a small sample of all the fathers of adults with AS or HFA. The advantage of the methodology used is that IPA aims to give an in depth understanding of individual experiences, rather than a large set of data that can then be generalised.

Overall the sample was reasonably homogenous, which brings both strengths and limitations to the study. IPA requires a commonality in the experiences of the participants, in this case the participants needed to be fathers of adults with AS or HFA. When all of the participants share common characteristics, it adds weight to the findings of a study being representative of that group. However, it also makes it less possible to assume that the results can be generalised to other people who do not share these characteristics. The fathers in this study were generally quite similar in their ethnic background, their home situation (i.e., married, living with wife and children, home owners), were working or retired and most of the fathers and adult children were of a similar age.

The seven participants were recruited through five different support groups in different counties, which provides some diversity of experience, as the support structures are not identical from county to county. However, all of these areas are in the South of England, near London and are areas that are mostly considered affluent. Some of the fathers in this study spoke about accessing private services for support, which would not be possible for many families.

Participants were recruited to this research study through communications to support groups for parents of people with ASC. This was a successful recruitment strategy, but does mean that the group are self-selected and were all involved already with this area of support. While the participants for this study were self-selected as they are the people that chose to respond to an email communication, a separate, probably larger group of people chose not to respond, for varied reasons which are likely to impact on their experiences. There is also another group of fathers who have chosen not to become involved with support groups, or are unaware of their existence.

6.8 Recommendations for future research

It would be interesting to further triangulate the results of this research by exploring it from different angles and with different methodologies. Dallos and Vetere (2005) describe triangulation as being: “based on the idea that different perspectives on the same phenomenon can enhance our understanding whilst at the same time can provide a basis for cross-checking and cross-referencing

our findings” (p.205). It would also be interesting to repeat this research with other groups of fathers to build up a picture of the similarities and differences in experiences for fathers of adults with AS or HFA.

The fathers in this study were fathers of both sons and daughters with AS or HFA. Further research could focus just on the fathers of daughters or just on the fathers of sons with AS or HFA, or could look at the differences between the experiences of fathers of daughters compared to sons. Research into how the experiences of females might differ to males with ASC was an area brought up by people with ASC, families and professionals in Pellican, Dinsmore and Charman’s (2014) survey of research needs in Autism. The experiences of fathers of females can be seen to further extend this area of research.

Fathers in this study were all from fairly affluent areas in the south-east of England and appeared to be financially secure. Further research could include speaking to fathers in other areas of Britain and from different financial circumstances, as it could be expected that difficult financial situations could lead to extra challenges for fathers and their families and could affect that availability of support. In addition, there was not very much perceived cultural diversity in the participants in this study, so further research could aim to recruit fathers from other cultural backgrounds. It could be interesting to consider the impact of cultural influences and traditional family styles on the experiences of fathers.

Recruitment for this study took place through support groups. Future research should explore ways of accessing those fathers who are not in touch with support groups and who are less in touch with services in general, in order to explore their experiences.

Three out of seven of the fathers in this study reported that their child had a diagnosed mental health difficulty. These mental health difficulties featured strongly in their communications of their experiences. Future research might wish to look further at the experiences of fathers of people with AS or HFA, who are also diagnosed with mental health difficulties, as fathers described a strong role of helping their child manage their mental health difficulties and a big impact on their own mood and wellbeing.

Fathers of people with AS or HFA have not been included or equally represented in most research of parenting a person with AS or HFA. However, there are also other people who may care for adults with AS or HFA and fathers in other situations, who are also under-represented in the research, such as extended family, partners, single fathers, step-fathers or separated fathers.

The interview represents one snapshot in time. Two of the fathers mentioned that their current view had been coloured by something that had happened that week, for example, Henry’s daughter had taken an overdose at the start of the week and Andrew’s son lost his job between the two halves of

his interview. It would be interesting to conduct some longitudinal research with fathers of adults with AS or HFA, in order to explore their experiences over different points in their families' lives.

6.9 Personal reflections

I wanted to end with a summary of what I feel I have learned both professionally and personally through the process of undertaking this research. This ties together the reflective process that can aid a reader's understanding of the position of the researcher.

The journey has been one of love and hate with this research, but a constant interest in ASC and an increasing respect for the fathers who were involved in my study. At times it has been difficult, for example, when hearing about some of the perceived failures of support services, to think of myself as part of these services. It has made me consider the way in which referrals are refused or accepted, the impact this may have on families and how to involve fathers more in interventions.

I have found that the process of undertaking this research has influenced my understanding of my clinical work. Part way through undertaking this research I have started working again with children with ASC, which I have found enriching to my understanding of the experiences of the fathers I interviewed. It has influenced my thinking around the families of the children and adults I work with and I have become very aware of the involvement (or absence) of the fathers within this work. The process has improved my awareness of my assumptions and biases in this area, such as, some tendencies to judge the ways in which families have dealt with the challenges of ASC.

In terms of learning new skills, this was my first foray into qualitative research and the process of completing this study has made me familiar with both IPA as an approach to analysis and the more generic skills for qualitative research. It has also given me cause to learn more about my learning and working style, which will serve me well in the future.

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8. List of Appendices

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APPENDIX A. Notifications of Ethical Approval

University of
Hertfordshire



UNIVERSITY OF HERTFORDSHIRE
HEALTH & HUMAN SCIENCES

ETHICS APPROVAL NOTIFICATION

TO Ellen Mackey
CC Nick Wood
FROM Dr Richard Southern, Health and Human Sciences ECDA Chairman
DATE 30/06/14

Protocol number: LMS/PG/UH/00247

Title of study: Father's experiences of living with their adult child with Asperger's/High Functioning Autism: an IPA study.

Your application for ethical approval has been accepted and approved by the ECDA for your school.

This approval is valid:

From: 01/07/14

To: 31/07/15

Please note:

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1. Should you amend any aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit form EC2. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

UNIVERSITY OF HERTFORDSHIRE
HEALTH & HUMAN SCIENCES

ETHICS APPROVAL NOTIFICATION

TO Ellen Mackey
CC Dr Nick Wood
FROM Dr Richard Southern, Health and Human Sciences ECDA Chairman
DATE 22/10/14

Protocol number: aLMS/PG/UH/00247

Title of study: Father's experiences of living with their adult child with Asperger's/High Functioning Autism: an IPA study.

Your application to modify the existing protocol LMS/PG/UH/00247 as detailed below has been accepted and approved by the ECDA for your school.

Modification: Extending the recruitment of participants through online support forums.

This approval is valid:

From: 22/10/14

To: 31/07/15

Please note:

Any conditions relating to the original protocol approval remain and must be complied with.

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1 or as detailed in the EC2 request. Should you amend any further aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit a further EC2 request. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Students must include this Approval Notification with their submission.

APPENDIX B. Literature Review Search Strategy

The literature search included 3 stages:

1. Online literature search
2. Review of references
3. Repeat of online literature search

1. Online literature search

I searched for journal articles and books using:

- University of Hertfordshire Online Library Search
- Google Scholar
- NHS Evidence search using PsychINFO
- Psycharticles
- Cinahl Plus
- Taylor & Francis Online
- PubMed.gov
- Science Direct
- Scopus
- Sage Journals
- The National Autistic Society
- ASC and developmental disorder specific journals such as Autism, The Journal of Autism and Developmental Disorders, and Research in Developmental Disabilities.

Words used in the search include:

Autistic spectrum condition	ASC Autism spectrum condition Autistic spectrum disorder Autism spectrum disorder ASD Autism Autistic Autistic disorder	OR
Asperger's	Asperger's Syndrome AS Asperger Aspie Asperger disorder	
HFA	High functioning autism	
AND		
Parents	Parental	OR
Fathers	Dad Paternal	
Mothers	Mum Maternal	

No restriction was placed on dates. This initial search included articles published up until December 2014.

Articles were excluded if they were not written or translated in English.

2. Review of references

I examined the references of all the articles found through the initial online search for any further relevant literature.

3. Repeat of online literature search

I repeated the online literature search to capture any articles published, or made available online between December 2014 and May 2015.

APPENDIX C. Participant Information Sheet.

Participant Information Sheet

Fathers' experiences of living with their adult child with Asperger's/ High Functioning Autism

Who is completing this research?

My name is Ellen Mackey and I am a Trainee Clinical Psychologist for Cambridgeshire and Peterborough NHS Trust, training at The University of Hertfordshire in Hatfield. I am inviting you to take part in a research study exploring the experiences of fathers who are living with their adult child with High-Functioning Autism or Asperger's Syndrome.

This research is being supervised by Dr Pieter Nel from the University of Hertfordshire, and Dr Pippa Barrett who is a Clinical Psychologist working with people with Autistic Spectrum Disorders.

The study has been approved by the University of Hertfordshire's Research Ethics Committee. The protocol number is LMS/PG/UH/00247.

What is the purpose of the research?

The purpose of this study is to explore the experiences of fathers who are living with their adult child with HFA or AS. The aim is to understand how you experience your role as a parent of an adult child with HFA or AS and the impact that living with your adult child has on your life and relationships.

This research is being carried out as part of the Doctorate in Clinical Psychology (D.Clin.Psy.) training.

What will I be required to do?

If you choose to take part in this study, you will be asked to take part in an individual interview at a place and time convenient to you. The interview will take up to 2 hours to complete. The interview will be audio recorded. The interview will involve questions relating to your experience of living with your adult child with HFA/AS.

The audio recording will then be anonymously transcribed (written out from the recording, removing identifiable information) and analysed. The recording and information will be kept securely and confidentially. An external transcription service may be used, which will also be bound by a confidentiality agreement. Only anonymised information will be available to supervisors and examiners. Anonymised quotes will be used in the report of this research. The audio recording will be destroyed after conferment of the Doctorate.

You may be contacted to comment on the accuracy of my analysis of your interview, i.e. whether the themes I draw from the interview are representative of your experience.

Will other people be able to identify me in the research?

All efforts will be taken to anonymise any information given during the study. However, given the small number of participants in this study and the community nature of support for carers of people with Autistic Spectrum Disorders, it is possible that people reading the results of the research may be able to identify you through details of your experience.

Will the information be confidential?

The information will be anonymised. However, if you were to say anything during the interview that made be concerned that you, or another person were at risk of harm I would pass this information on for safeguarding purposes. I would always try to discuss this with you at the time if it were appropriate.

Can I choose whether to participate in this research?

You can choose whether to participate in this research, and will need to complete a consent form if you choose to participate.

You can withdraw your consent at any time during this study, and do not need to provide a reason for withdrawal.

If you have already completed the interview and choose to withdraw your consent for the information to be used, the audio recording and transcription will be destroyed and your information will not be used.

If you have any questions about the study, or feel that you have suffered any adverse effects from taking part in the study you can contact the researcher and supervisors on the contact details below.

What happens to the results of the study?

This study is being undertaken in partial fulfilment of Ellen Mackey's Doctoral training in Clinical Psychology, and a Major Research Project Report will be submitted to the University of Hertfordshire. The results of the study will also be submitted for publication in a relevant journal.

You can request to receive feedback on the results of this study by contacting the researcher or supervisors on the contact details below.

How can I contact the researcher?

If you have any questions or concerns regarding the above you can contact me on the following details:

Ellen Mackey, Trainee Clinical Psychologist

Department of Clinical Psychology, University of Hertfordshire, College Lane, Hatfield, AL10 9AB.

E-Mail: e.mackey@herts.ac.uk

If you have any comments or complaints to make about your involvement in this research, please contact my supervisor, Dr Pieter Nel, or the Ethics and Research Chair, whose details are below.

Name of supervisor:

Dr Pieter Nel;

Email: p.w.nel@herts.ac.uk

Department of Clinical Psychology; University of Hertfordshire, College Lane Campus, Hatfield, AL10 9AB. Tel: 01707-284767

Dr Richard Southern

Chair: HHS ECDA Committee

Faculty of Health and Human Sciences, University of Hertfordshire. AL10 9AB

Ethics Protocol No: LMS/PG/UH/00247

Thank you for participating

APPENDIX D. Consent Form

Fathers' experiences of living with their adult child with Asperger's/ High Functioning Autism: an IPA study.

The purpose and process of the study has been explained to me: ☐

I understand the purpose of the study: ☐

I am willing to participate in the study: ☐

I understand that I can withdraw from the study at any time, and do not have to give a reason for my withdrawal: ☐

I have been provided with contact details for the researcher and supervisor, should I have any questions or want to withdraw: ☐

I understand that the information I provide will be kept secure and confidential and viewed by authorised persons only: ☐

I understand that I am able to request to view the findings of the study after completion: ☐

I understand that my interview will be audio recorded: ☐

I understand that the research is being completed as part of Ellen Mackey's Doctorate in Clinical Psychology and will be submitted and assessed as part of the training qualification: ☐

Name

Signature

Date

APPENDIX E. Participant De-brief Sheet

Fathers' experiences of living with their adult child with Asperger's/ High Functioning Autism: an IPA study.

Thank you for being involved in this research study. Your participation will be helpful in gaining an understanding of the experiences of fathers who live with their adult child with HFA or AS.

The information provided by you in your interview will now be anonymously transcribed and written up to be included in the research findings. If you would like to receive a copy of the overall research findings please contact us.

If you have any further queries and wish to contact the researcher, you can do so by using the following details:

Ellen Mackey
Trainee Clinical Psychologist
Department of Clinical Psychology, University of Hertfordshire, College Lane, Hatfield, AL10 9AB.
Tel: 07890906368
E-Mail: e.mackey@herts.ac.uk

If you have any further need of support, please contact:

The National Autistic Society:
www.autism.org.uk or the NAS's Autism Helpline on 0808 800 4104.

Your local NAS branch:
Tel:
Web link for contact:
Email:

Or

Carers in County
Telephone number:
Fax number:
Web link for contact:
Email:

The research is being supervised by Dr Pieter, Clinical Psychologist and he can also be contacted on the following e-mail address: p.w.nel@herts.ac.uk.

Thank you for your participation

APPENDIX F. Information about participant form

Information about participants.

Participant number:

Participant age:

Participant occupation:

Information about participant's child with HFA/AS:

Age:

Gender: (m/f)

Occupation:

Other members of household:

Spouse/ partner? Yes/No

Occupation:

Other Children:

- | | | |
|---------|---------|------------------------|
| 1. Age: | Gender: | Living at home: Yes/No |
| 2. Age: | Gender: | Living at home: Yes/No |
| 3. Age: | Gender: | Living at home: Yes/No |
| 4. Age: | Gender: | Living at home: Yes/No |
| 5. Age: | Gender: | Living at home: Yes/No |

Information about participants 2 (kept separately)

Participant number.....

GP Details:

(only to be used if interviewer is concerned for safety of yourself or others)

GP Name:

GP address:

GP contact number:

APPENDIX G. Semi-Structured Interview Schedule

Semi-Structured Interview Schedule

Child's name:

Role

Please can you tell me a bit about yourself?

Please can you tell me a bit about your family?

Can you tell me about your role as the father of X at the moment?

Has your role as the father of X changed over time, and if it has, how has it changed?

Does being the father of X impact on other roles you may have? For example, at work, socially etc.

Relationships

Can you tell me about your relationship with X?

Do you think being a parent to, and living with X, has an impact on your relationships with:

- Your partner
- other members of your family
- and friends?

Support

Can you tell me about your experiences of accessing support for X?

Can you tell me about your experiences of accessing support for yourself?

The Future

How do you feel about X's future?

What are your hopes and/or fears for the future?

This interview

Is there anything else you would like to share?

What has it been like to talk about your experiences?

Will you talk to anyone else about this interview later?

APPENDIX H. Anonymised analysed transcript of the interview with 'Charles'

Participant:	6

Developing Emergent Themes				
Emergent themes	Line	I/P	Original Transcript	Exploratory comments
<p>Story of changes and progress</p> <p>Impact of Asperger's</p> <p>Developing understanding.</p> <p>Developing understanding.</p>	1	I	<ul style="list-style-type: none"> Can you just tell me a bit about yourself? 	
	2	P	<ul style="list-style-type: none"> Um, in terms of what, working life or home life or? 	
	3	I	<ul style="list-style-type: none"> Whatever's important about you to...? 	
	4	P	<ul style="list-style-type: none"> Anything, well OK. I, I lived in Wales till I was 22, and came to University/town to do a 	
	5		PHD, I intended to go back up north after that, but met my wife and got a house and	
	6		got a job, and before you know it, life kicks in and um. And here I am. Um we had our	What does life mean?
	7		daughter 20 years ago, so, I think we were married about 7 years when she came	
	8		along. Um, and she was uh, a lovely child when she was small, um, but even from a	Lovely child when she was small
	9		very early age, we noticed some, strange behaviour from her really. There would be	Strange behaviour
	10		little interest in other kids at a birthday party for instance, the social connectivity	Little interest in other kids. Social Connectivity
	11		wasn't there, and we just, we put it down to kids just being a bit different. But later	Kids just being a bit different.
	12		on we discovered, you know, that, that, the triad of impairments includes social	Triad of impairments. Knowledge of ASC.
	13		difficulties.	Understanding
	14	P	<ul style="list-style-type: none"> And, once we learned a bit more about Asperger's we were able to look back and see 	Learning.
	15		some of those traits, way back to you know, 1 and 2 and 3 years old, and we started	Looking back. Way back Traits

Need for understanding	16			to twig that that was actually what had been happening. Um, so, school years were	Actually what had been happening.
Struggle and emotional distress	17			quite difficult, um my daughter was bullied, and she found school tremendously	Understanding. Difficulty
Distress as a parent to see child struggle	18			difficult, because her organisation is really quite impaired. She would be slow, she	Quite> tremendously
Impact of Asperger's	19			was a slow worker, she ur, invar, she looked like she was day dreaming. In fact I think	Organisation is really quite impaired.
Different perceptions	20			she was paying quite a bit of attention cos a lot of what was taught seemed to go in,	She looked like she was day dreaming.
	21			but she really did struggle with getting anything finished on time. She could, couldn't	Others perceptions.
	22			really make decisions about what to do first, or how much to do, so school.	Impairment. Really did struggle
Bumbling through	23	P		<ul style="list-style-type: none"> Primary school was, we kind of bumbled through it I guess. We did ask for, some help 	We kind of bumbled through.
Seeking support	24			from psychiatric, was a psychiatric worker who came to just assess my daughter, um,	Ask for some help
	25			and he just said she's slow. She's very intelligent, but she's slow and that's it. Nobody	She's very intelligent, but she's slow.
Need for understanding	26			in the primary school twigged, that there was a, a autistic thing going on. Um, not	Let down. Nobody twigged.
Feeling let down by services	27			any teachers, not any psychoanalysts, or.. we took her to the doctor, we were quite	Autistic thing going on.
Seeking support	28			concerned cos there was some self-harming kicking off at this time. She was so,	Not any....
	29			becoming so stressed, um about situations at school, that she was starting to self	Quite concerned
Distress as a parent to see child struggle	30			harm. And that would typically involve hitting herself in the face. Um, which is really	Starting to self harm
	31			quite distressing when your child starts to do stuff like that.	Really quite distressing when your child starts to do stuff like that.
	32	P		<ul style="list-style-type: none"> Um, in conflict situations, if somebody, another of her peers, say, um, would 	
Developing understanding	33			threaten her or tease her or irritate her, she would hit herself. And she rationalised	She rationalised that.. In comparison to his understanding.
	34			that by saying, well, they want, to hit me, why don't I just get it over with, I'll do it	
	35			myself. That'll, that'll satisfy them and they'll go away. She saw it as a route to	Route to resolving the difficult emotional situations.
	36			resolving the difficult emotional situations that she was in.	

Distress as a parent to see child struggle	37	P	<ul style="list-style-type: none"> So you can imagine that, you know my wife and I were just kind of getting more and more concerned about how she was dealing with life. And she went to secondary school, and a, things kind of went from bad to worse there. Although the, there was a learning support department, um, the ability for the school to support kids like my daughter was extremely limited. They were just under resourced. And any resource that they had, need to be directed towards kids with statements. Um, we tried hard to, we went through the medical, a medical route, the surgery to be referred to a specialist to try and get a diagnosis of some kind. Put, put my daughter through a series of tests, and. And even from an early age she had been put through some tests in CAM H, up in, University/town mental health, is that right? Is that what CAM H is? They put her through a series of tests, none of them indicated autism, none of them really indicated autism. 	Getting more and more concerned about how she was dealing with life.
Struggle and emotional distress	38			
Story of changes and progress	39			Went from bad to worse
	40			Ability of the school.
Feeling let down by services	41			Lack of support
Services under-resourced	42			Under resourced
	43			Importance of statement.
Seeking support	44			Seeking help- need for diagnosis to get support
Diagnosis as helpful	45			
	46			
Feeling let down by services	47		<ul style="list-style-type: none"> And she wasn't, this was the thing that really got to us I think, she wasn't bad enough to merit any further support. And that has been a common thread throughout our whole experience of this, is that, living at home with someone with Asperger's, you see how they struggle with life. To meet my daughter, if you were to meet my daughter in an environment like this and talk to her, you'd be, in common with most of the rest of the world, you'd say that's a lovely young woman, competent, articulate, intelligent, what's the problem, you know, what's the problem? 	None of them, none of them
	48			
	49	P		She wasn't bad enough to merit
	50			Common thread throughout
	51			See how they struggle. Witnessing
Distress as a parent to see child struggle	52			
Different perceptions	53			Other's perceptions.
	54			In common with most of the rest of the world
Seeing her strengths	55			
Need for understanding	56	I		What's the problem?
	57	P	<ul style="list-style-type: none"> yep And that, I think that's what we have had to face all along. It's only at home, when you see, the details of, of what's going on. The state of her bedroom. And you say 	WE have had to face
Distress as a parent to see child struggle	58			It's only at home when you see the details of what's going on.

Impact of Asperger's	59		hey, maybe it's time to tidy this up, and she says ok. And you come back 4 or 5 hours	
	60		later and there's nothing changed, and there's nothing changed, not because she's	Frustration. Nothing changed.
	61		lazy, but because she doesn't know where to start. There's an infinite amount, and	Understanding.
	62		infinite number of decisions to make, what do I do with this? Where does it go?	
	63		Should I throw it out? Should I keep it? Um, she, she just can't make those split	She just can't make those split second decisions
	64		second decisions.	
Distress as a parent to see child struggle	65	P	<ul style="list-style-type: none"> So the whole of life is coloured, of her life is coloured by a disability to uh, cope with 	Whole life is coloured
Impact of Asperger's	66		decisions rapidly. Um, some things don't need rapid decisions, some things do. Um,	
	67		and she struggles with that. SO back to, am I, is this train of discussion helping, is	Struggles
	68		this?	
	69	I	<ul style="list-style-type: none"> Yeh, go where you want with this. 	
	70	P	<ul style="list-style-type: none"> Ok, I'm trying to just draw a thread of past experience through, I'm trying to 	Draw a thread of past experience
	71		ultimately get to where we are just now. Um, uh, and I think we got to 13, she was	Gave up, let down.
Feeling let down by services	72		13 when eventually we gave up with school we gave up with drs, we explored a	
Seeking support	73		private uh, child psychiatrist, um, who, spent, 5 or 6 2 hours sessions with my	
	74		daughter, wrote a report on a, she went through a whole bunch of tests, uh,	
	75		standardised tests to come up with a report, in which she said my daughter is on the	
Developing understanding	76		autistic spectrum, and I can recommend that you do all this stuff she said, to deal	
	77		with the organisation you need to be thinking about smart pens, you need to be	Need to be..
	78		thinking about uh, mind maps, you need to be thinking about, a whole list of really	
	79		uh, valuable information that the school ought to have known about, that CamH	Valuable information
Feeling let down by services	80		ought to have known about, um.	What others ought to have known.

	81	P	<ul style="list-style-type: none">We took the report from the child psychologist to the school, and we went to the senco and we put it on his desk and said look we've got a report now that says that my daughter is on the autistic spectrum. He didn't even look at it, he said, that's great, let's get a statement. I, and we did, we got a statement for 27 and a half hours, of TA support, and I don't know if you, if you're aware of what that means, they can't give you any more than that, that is the full statement. SO it seems to me somewhat strange that a person who, um, seems to slip through all the analysis that primary and secondary schools so that drs do, ends up with 100 percent TA support. And needs it. Um, yeh, the, the support was provided by the county, I would say the school, even then, the school did not deliver on that support. Because there's an element, and we went along with that to a degree, there's an element of, um, you want to encourage this person to become independent. In order to do that, you give support, but you also train them as you withdraw the support to stand on their own feet. It never really works, the support was withdrawn, but the monitoring of how my daughter was doing was not good.	
	82			
Seeking support	83			Opening doors
Diagnosis as helpful	84			Importance of diagnosis in getting support
	85			They can't give you any more than that
	86			Validation// relief?
Distress as a parent to see child struggle	87			Somewhat strange.
	88			Let down.
	89			Impact of ASC- needing support
Feeling let down by services	90			Did not deliver
	91		What is best to do?	
Importance of independence	92		Independence	
	93			
	94		Never really works.	
Feeling let down by services	95		Monitoring not good,	
	96	P	<ul style="list-style-type: none">So, we were perpetually badgering the school. Finding out, how's this going, what's happening, whys she not getting support, what's going on. Every meeting we would have with the senco, would sound, there would be lots of really good sounds coming out, but the delivery was poor. Didn't happen, didn't work. Um, she went to, she left that school, because it didn't offer a sixth form, she went to a different school for sixth form, she has uh, come out with some excellent A levels. She's now studying at	Perpetually badgering
Need to badger to get support	97			Needing to know what's happening
	98			Lots of good sounds- poor delivery
Feeling let down by services	99			Didn't happen, didn't work
	100			
Seeing her strengths	101			Excellent A levels.
			Importance of academics.	

Seeing her strengths	102		University/town, so the academic ability is unquestionable, she has all the academics you could ever hope for.	She has all the academics you could ever hope for. What other hopes?
	103			
Impact of Asperger's	104	P	<ul style="list-style-type: none"> That's not her disability, her disability lies in organisation, in self-management in emotional in social, in all of the stuff that you know about, to do with Asperger's. 	Disability All the stuff to do with asperger's.
	105			
	106		Um, and indeed at the university she has a huge amount of support organised through the disability, department. I can't remember what it's called. Um, so they're	Huge amount of support. Good support
Good support lets life flourish	107		doing a fantastic job actually, of, of making adjustments, for her disability and recognising it. It's possibly the first time that it's been recognised so well. Maybe	Fantastic job.
	108		that's because University/town is full of autistic people, I don't know.	Possibly the first time that it's been recognised so well.
	109			
Good support lets life flourish	110			
	111	P	<ul style="list-style-type: none"> Um, but there, there you go, that's kind of where we've got to. We've got to now 	
	112		.The academic stuff is, is. With support her academic stuff is, life can flourish. But the	Life can flourish. Academics=life?
Distress as a parent to see child struggle	113		support is needed, she cannot do it on her own, because um, she really can't look	Cannot do it on her own. Need for support.
	114		after herself on her own. She's got, she's at college at the university, it's a catered	
	115		situation so she doesn't have to bother about cooking, or shopping, she's, 7 miles	
	116		away from home, so if, push comes to shove we can see her in half an hour. You	
	117		know, we don't have to travel hours to get to the university. SO that's a good	Good to be close.
	118		situation for her to be in.	
	119	P	<ul style="list-style-type: none"> Let me just unwind a little bit, cos that's, that's the trail of the timeline for my 	Unwind the story. Trail of the timeline.
Difference leading to tensions in relationships	120		daughter. About the same time as, um, as, my daughter was diagnosed, things were	
	121		getting quite difficult for my wife and I. The relationship was somewhat strained. And	Strained marriage
	122		that was really down to me, um, I didn't cope at all well with that diagnosis. In fact it,	Down to me. Taking responsibility for it.
Diagnosis as bereavement	123		it, I'd possibly describe it as the worst thing that's happened to me in my life so far. It	Worst thing that's happened in my life so far.

Diagnosis as bereavement	124		was, it was like a bereavement, um, and again this is something I've found that not	Bereavement ++
Feeling separate	125		many people can relate to. It was like a bereavement, because, the daughter that I	Not many people can relate.
Diagnosis as bereavement	126		thought I had, um, had suddenly gone. The diagnosis took that away, in my head,	Diagnosis took that away.
	127		although I could see how much she was struggling, in my head I thought, its kids, you	
Diagnosis as helpful	128		know, it's tough times. We will get through this, um, the diagnosis helped her.	Helped her.
	129		Suddenly she was, she was, freed of, of self-doubt, she understood there was	Bereavement vs helpful for her.
Developing understanding	130		something different, that could explain why she was feeling how she was feeling,	Explanations, Why.
	131		why she behaved the way she did.	
Diagnosis as bereavement	132	P	<ul style="list-style-type: none"> For me the opposite was true, the diagnosis was like a bereavement, because it took 	Different view.
	133		away all hope that the person I thought I had was still there. I had to replace that, I	Bereavement++
	134		had to allow that person to die, in a sense. And to replace, to replace my image of my	Replace my image
Diagnosis as bereavement	135		daughter with something different. And that I think was as close to a bereavement	
	136		process as I can explain. And I don't think, you know, people would tell me, oh your	Other's perceptions
Different perceptions	137		daughter's still your daughter, I never found that a very useful, a very useful thing.	
Difference leading to tensions in relationships	138		So, going through this sort of bereavement blackness, um, and I, I don't know about	Bereavement blackness
	139		the other 5 or 6 guys that you've talked to, but, my experience of me, is that I don't	Other fathers
Not understanding self	140		really understand my emotional responses very well.	Don't understand emotions
	141	P	<ul style="list-style-type: none"> I think I was depressed, now. I think I can understand, and my wife I think, certainly 	Depressed
Struggle and Emotional distress	142		understood that I was depressed. But at the time, I would have said no, absolutely	Wife saw things differently
	143		not. I'm angry, I'm upset, I'm all sorts of stuff, but depressed? No. I think I was wrong,	Depression not acceptable.
Not understanding self	144		um, because there was a lot of low mood. And the way that I dealt with that,	
Positioning in relation to others' experiences	145		probably in common with most men, was by, by separating myself from the problem.	Coping through separation. Avoidance.
Coping through avoidance				

Coping through avoidance	146		I would have, I bought myself a big motorbike and drove off, you know, to relax, to	Get out of the situation.
	147		get out of the situation that I was in, I would go off to the forest somewhere on this	
	148		bike, park the bike up get some running gear on, and run round the forest for 10	
Coping through avoidance	149		kilometres. Um, exercise and motorcycles were what helped me through this, this	Helped me through this, this strange stage.
	150		strange stage.	
	151	P	<ul style="list-style-type: none"> Well at least it helped to, it was a cathartic, you know, get rid of some energy, get rid 	Cathartic.
	152		of some stress. It didn't actually solve the problem. Uh, the problem in my head was,	Didn't actually solve the problem.
	153		was that whilst my wife, three of us obviously, wife and daughter, and father, me.	Problem in my head.
Feeling separate	154		And I looked at my family and I saw a strong bond of relationship between my wife	
	155		and my daughter, and I saw myself as separate to that. I saw them as a team and me	I saw myself as separate to that.
	156		as separate. Um, and I think that's, that that was, emphasised because the two of	Separate
	157		these folks really did get on very well.	
	158	I	<ul style="list-style-type: none"> Right 	
Difference leading to tensions in	159	P	<ul style="list-style-type: none"> Whereas when I tried to interact with my daughter, there was tension, there were 	Tensions
relationships	160		tensions there. I didn't understand autism, I didn't understand Asperger's. Teenage,	Not understanding
Need for understanding	161		you know I expected some teenage behaviour, and I thought what I was seeing was	Just teenage behaviour
Role as father	162		just teenage behaviour. And, and I had to be a dad, I had to be a father to that. So, I	I had to be a dad, I had to be a father to that
Importance of independence	163		was driven to make my daughter independent, I would expect her to be independent	Driven to make my daughter independent
Impact of Asperger's	164		in ways that she just couldn't be yet, because the Asperger's didn't allow her to be.	Asperger's didn't allow her to be.
	165		So there's a bunch of tension going on there. So this, this just got stronger, this	Tension.
Feeling separate	166		partition of our family relationship between me and them, got stronger. And my wife	Partition got stronger
Different perceptions	167		sensed it. She didn't see it that way at all, she want, she felt strongly that what we	She didn't see it that way at all.

Strength as a team	168		should have been exhibiting and what we needed to work together was the two of	Needed to work together
	169		us, working with our daughter, you know, the family life, but the two of us together	
Different perceptions	170		as a team, working with my daughter. And, this just didn't feel true, it wasn't true to	Truth/ perception
Feeling separate	171		me. This was the truth of it (partitioned)	
	172	P	<ul style="list-style-type: none"> Um, and so the, what camh did for us, because my daughter, through, through 	What CamH did for us.
Diagnosis as helpful	173		getting her statement, through getting her diagnosis, camh did eventually wise up,	Importance of diagnosis in getting support
Developing understanding	174		did accept that there was some work to do here. I think it was her self harming that	Some work to do
	175		actually opened the doors there. It needed to be like that before camh would work	Self harming
	176		with her. And because camh was seeing my daughter, they also saw us as a family.	Needed to be like that before camH would work
	177		And we, we went to see a family, relationship, therapist, is that it? Is that what they	with her
	178		call them, a family relationship therapist,	
	179	I	<ul style="list-style-type: none"> yep 	
Story of changes and progress	180	P	<ul style="list-style-type: none"> Um, and that was the start of my recovery, because I, that guy helped to to, helped 	Start of recovery through understanding
Own beliefs affecting interactions	181		me to understand why I was thinking the way I was thinking, why it was wrong, um,	
	182		how I needed to think about my daughter and my wife and the relationship	
Life transforming therapy	183		surrounding it. Just a better way, a better way to be. Instead of having a crusade, to	Better way
Importance of independence	184		make my daughter independent, I needed to just work with who I had. Um, to be a	Crusade to make my daughter independent
Own beliefs affecting interactions	185		dad to her, rather than to try and be a, a, be something else. Um, so that was about 4	Be a dad to her.
Role as father	186		years that we saw a family relationship therapist at Camh, it was the most, life	It was the most life transforming experience I
	187		transforming experience I think I've had. And I, I, wonder what I would have done	think I've had.
Life transforming therapy	188		without that actually, I think our marriage was probably in jeopardy,um, certainly the	Marriage and relationship in jeopardy.
Difference leading to tensions in	189		relationship with my daughter was in jeopardy. So that, that helped to transform a	Transform
relationships				

Story of changes and progress	190		really quite difficult situation, and turn it around. And, uh, you know, I'm, I would be	Turn it around.
Advice to other father	191		keen to just get the message out to other men who are in the same position, that	Message to others
	192		you can't just go out on your own, on motorbikes or runs round forest, you need to	Need to talk
	193		talk about this stuff.	
Positioning in relation to others' experiences	194	P	<ul style="list-style-type: none"> And it doesn't come naturally to guys. Guys just want to go off in their cave I think. 	Doesn't come naturally to guys.
Life transforming therapy	195		But this was a talking therapy that really, that really um, saved us I think. There you	Saved by therapy.
	196		go, there's an opener to..where do you want to go from there?	
	197	I	<ul style="list-style-type: none"> Yeh, lots of information in there, um, I guess, could you just explain a bit more, 	
	198		maybe about your family, so about your wife and daughter and if there's any other	
	199		important people.	
Feeling separate	200	P	<ul style="list-style-type: none"> Well, the rest of our family are up in Wales, so of necessity they are somewhat 	Of necessity somewhat distant. Just geographically?
	201		distant, um, so in terms of important people, my wife, she's Welsh too, we met in	
	202		University/town. She tried to go out to work shortly after our daughter was born,	
Fixed role of mother	203		um, but she needed her mum to be around, so we shelved that for a while. But never	Life put on hold
	204		really got back to it. The amount of support that my wife needed to provide. Um, was	Little question over whether support should come from mother.
	205		just too much, she couldn't hold down a job, and support my daughter at the same	
Need to badger to get support	206		time. Um, the support invariably involved telephones to the school, emails to the	
	207		school, trying to talk to TAs, trying to find out what's going on, and chasing them.	Chasing. Can't trust to just do.
	208		Um, we found that if you just let it alone, if you stood back and just let them do what	
	209		they do, you would not get a good service. To get anything approaching a good	
Feeling let down by services	210		service you had to stay on top of them. Um, shouldn't be that way but that was our	Shouldn't be that way.
	211		experience.	

Seeing her strengths	212	P	<ul style="list-style-type: none">Uh, so, my wife is, my daughter's just gone to university, in October, so that was her first term, so we're still accommodating that change, and try to figure out what to do, what to do next and how to do it. Uh, I mean other personal, my father just died in October as well, so um, what, when we, thought we were going to be, have a little bit more time to ourselves, suddenly we're into this probate situation. Um, so, that, that will pass of course, we had just hoped that we'd get a little bit more time, and then, no.	Accommodating that change		
Story of changes and progress	213	P				
	214				Father died	
	215					
	216					
	217				More time	
	218					
	219					
Need for understanding	220		P		<ul style="list-style-type: none">So, those are the important folks around. I would say, we're both members of a church, we're all members of a church. Um, Again, the church just didn't understand, you would expect the church to have pastoral, um, you know folk in it who knew about how to, uh, pastor folks. How to deal with suffering, how to deal with emotional suffering and so on. Nope. Didn't really, didn't really work. So, I almost, almost every avenue that we tried to explore, just couldn't understand. You've got a fantastic daughter, she's really great, what's your problem. That's kind of how it felt. Um, so yeh, I think, if I were to summarise, any, any advice I would say fathers really do need to find, need to find some, somebody else who can reach them at the level they're at, and understand the situation they're in. Um, and encourage them to, to think differently, um about this. Education I suppose. You know you can say about the triad of impairments and we can all nod, but until you actually live with it, it is really hard to, just understand how far reaching it can be.	Both > all
	221					Church just didn't understand. Expectations let down.
	222					Suffering.
Struggle and Emotional distress	223					Let down
	224					Almost every avenue..
Feeling let down by services	225					Couldn't understand
	226					Fantastic daughter
Different perceptions	227					What's your problem.
	228					
Advice to other fathers	229	Other fathers				
	230					
Need for understanding	231					
	232					
	233					
Developing understanding	234	P		<ul style="list-style-type: none">I'll give you an example, um, how many examples do you want. Um, my daughters coming back home on the bus. Um, from University/town to, to our village, and she		Too many possible examples?
	235					
	236					

Story of changes and progress	234		presses the button to get off at her stop. But the bus is full, and there's people	Solving problems
	235		standing in the corridor, uh, so she can't get off without you know, scuse me, tapping	
	236		some shoulders, saying scuse me, and pushing to the front. So, her solution to that is	
	237		to stay on the bus, because that's too difficult. She stays on the bus until all those	
	238		folks have got off, by this time she's in .., and the bus drivers saying, you getting off	
	239		now darling, and she says, no I'm going back, so she stays on the bus all the way back	
	240		to, I think that she changed her seat so that she could get off easier when her stop	
	241		came. But, um, and 4 years ago if I was to hear that story I would get angry, I would	
	242		get angry with her for not being more assertive, for not, you know, telling the guy	
	243		you need to get past, raise your voice, make yourself clear, you know, get what you	
Own beliefs affecting interactions	244		want. Um, and I think the family therapist said, well, ok, she wasn't in danger, um, it	Changes
	245		was going to take her an extra hour to get home, but, that's OK she had the time, so,	
	246		you know she, she did, she did deal with the situation in a way that she felt was	
	247		acceptable. You mightn't think that it's acceptable, but she got herself home, she just	
	248		did it in a really wacky kind of way that just doesn't make any kind of sense to you,	
Developing understanding	249		but she's not you and you just have to, you know, get yourself into her mind-set.	Thinking differently
Difference leading to tensions in relationships	250	P	• Um, my, just to explain a little bit more of the tension. Between father and daughter,	
	251		my, you need to just, to tell me to stop or,	
	252	I	• No, I will if it's necessary but	
	253	P	• Cos, I understand that you've got questions here and	
	254	I	• but, you're, you're talking about things I'll be asking about, so	
	255	P	• Ok, OK, um so my, my background if I go back to my university, err, experience.	

Importance of independence	256	P	<ul style="list-style-type: none">My whole world view was, worked really hard at school to get good grades, to go to university, to get good grades, to get a good job, to get, well paid, to become independent, and to have choices. So there we go. In order to reach each of those milestones I was prepared to dedicate myself to it, so I worked my socks off, I think my organisational skills are quite good, um, I can plan, I can anticipate, I can manage risk, um, I can do all sorts of things that put me in a position to allow me to become financial director in a, in a high tech company in University/town. SO you put somebody like that, next to somebody whose, whose, who tries to work hard, but gets stuck because of the organisational difficulties with her, and you can see that there could be some sparks here. I want my daughter to do just as well as me, if she's going to do just as well as me, she needs to behave like I behaved.	Importance of working hard
	257			Planned out life.
	258			Importance of independence
	259			
	260			Organisation
	261			
	262			
Difference leading to tensions in relationships	263	P	<ul style="list-style-type: none">So I'm trying to mould this person, into the same kind of person that I was, but its square pegs and round holes. That's never going to fit. Um, that takes a long time to learn, guys don't learn that easily. Um, you know, I love exercising, I cycle to work, I go running, through forests. My daughters not like that, she doesn't want to run, so you've got all these areas of potential conflict, where, where I'm thinking as a father I've got to bring this person on, and, and give her the skills that I think she needs, to navigate through life. Skills that I've got that I want to give.	SO you put somebody like that, next to somebody.
	264			Organisation
	265			Sparks.
Own beliefs affecting interactions	266	P	<ul style="list-style-type: none">So I'm trying to mould this person, into the same kind of person that I was, but its square pegs and round holes. That's never going to fit. Um, that takes a long time to learn, guys don't learn that easily. Um, you know, I love exercising, I cycle to work, I go running, through forests. My daughters not like that, she doesn't want to run, so you've got all these areas of potential conflict, where, where I'm thinking as a father I've got to bring this person on, and, and give her the skills that I think she needs, to navigate through life. Skills that I've got that I want to give.	I want my daughter to do just as well as me.
	267			She needs to behave like I behaved.
Difference leading to tensions in relationships	268	P	<ul style="list-style-type: none">So I'm trying to mould this person, into the same kind of person that I was, but its square pegs and round holes. That's never going to fit. Um, that takes a long time to learn, guys don't learn that easily. Um, you know, I love exercising, I cycle to work, I go running, through forests. My daughters not like that, she doesn't want to run, so you've got all these areas of potential conflict, where, where I'm thinking as a father I've got to bring this person on, and, and give her the skills that I think she needs, to navigate through life. Skills that I've got that I want to give.	Mould this person
	269			Square pegs and round holes
	270			Learning. Ideas about men.
Role as father	271	I	<ul style="list-style-type: none">mm	Potential conflict.
	272			Thinking as a father.
Importance of independence	273	P	<ul style="list-style-type: none">Trouble is she doesn't want those skills. She doesn't want to know how to run, or drive a motorbike, or. She doesn't want to know how to organise her room or any of those things, so, you know, you can see where those tensions apply. And the talking	Skills to bring this person on.
	274			
Difference leading to tensions in relationships	275	P	<ul style="list-style-type: none">Trouble is she doesn't want those skills. She doesn't want to know how to run, or drive a motorbike, or. She doesn't want to know how to organise her room or any of those things, so, you know, you can see where those tensions apply. And the talking	She doesn't want..
	276			Rejected?
	277			Tensions

Life transforming therapy	278		therapy was just so crucial to getting me past it and onto a more solid footing. There	Therapy was just so crucial.
Story of changes and progress	279		was another thought that just went through my head, in all this talking, I'll just try	Past it
	280		and recover it. I'm sorry, it's gone, I'm sorry it's gone. Um.	Onto more solid footing. Feeling unstable before?
	281	I	<ul style="list-style-type: none"> Can I just ask you to tell me a bit about the role, your role as the father of your daughter at the moment? 	
	282			
	283	P	<ul style="list-style-type: none"> At the moment? 	
	284	I	<ul style="list-style-type: none"> Yeh 	
	285	P	<ul style="list-style-type: none"> Um, well it probably needs to be up to October I guess. I mean the last, the last three 	
Role as father	286		years have been focused seriously on getting A levels and getting university place.	Importance of academics
	287		Um, I guess you question is, in what way have I been a dad to her. Um, it's interesting	
Need for understanding	288		I often ask her that, or not often, occasionally I'll say how, you know, how can I be a	
	289		dad to you, how can I be a dad to you, what can I give you, um, that, you'll find	How can I be a dad to you?
	290		valuable. You know, I can do all this stuff, but I'm not sure you want it, um, how, how	Curiosity about what she wants/needs
	291		do I, I suppose it's just, I'm not really asking for affirmation from her, I'm really just	
	292		interested to know what she thinks she needs from me.	
	293	P	<ul style="list-style-type: none"> Invariably she says, I don't need anything dad, you know I'm just, I, I, I think your 	
	294		great as it is, um, and, uh, you know, let's just carry on as we are. Um, so, I, I think,	Lets just carry on as we are.
Story of changes and progress	295		since what did I say, we got the diagnosis when she was 13. Probably by about 14 we	
	296		were seeing camh and going through the, so 14-17 , 3 years of that. So that would	Working out where in time.
Healing of relationships	297		have ended 3, 2 or 3 years ago I guess. And during that 2 or 3 year period I think my	
	298		relationship with my daughter has calmed down a bit, um, it's become more. I've	Relationship with my daughter has calmed
	299		tried to make it more of an equal thing, rather than an authorat, you know a	down.

Own beliefs affecting interactions	300	P	<p>hierarchical authoritarian kind of thing, unless she really is going to go off and do something really daft. I, I, would just let her, you know, do the things that she does, in the way that she wants to do them.</p> <ul style="list-style-type: none"> That, that is quite hard actually, to see someone doing something, that you think, there's at least 2 ways of doing that better, or quicker or more efficiently. But you just have to, um, Oh I remember what I was going to say to you. The crusade as we used to call it, this, this um, insatiable, unquenchable desire to make my daughter independent, that's what, the family, my wife and I now call the crusade. Um, usually involved me being quite assertive. I'd say to my daughter, right, we're going to do this now, or, or sometimes, very, very rarely she would say, dad I need some help with this homework, and I would dive right in there, and, and just, you know. My teaching style is just I suppose, is not to give answers, but to help someone discover the answers for themselves. 	Letting go.
	301			
	302			
Distress as a parent to see child struggle	303			Quite hard actually- sitting back.
	304			Thinks can do better.
	305			Crusade to make independent.
Importance of independence	306			
	307			Have talked about it.
Own beliefs affecting interactions	308			Assertiveness
Role as father	309			
	310			Eager to provide help.
	311			Give knowledge.
Developing understanding	312	P	<ul style="list-style-type: none"> That wasn't what my daughter wanted. She just wanted the answers, so um. Part of the stuff that we got at camh was just the understanding that when she asks for help, before you dive in there, you need to ask, what kind of help you want. Do you want me to dive in? Or do you want me to just listen to what you're thinking about, or you know, how, let's just firm up a bit on how, what kind of help you want. So that extra step, um, and I think that's added a softness to the relationship, whereas prior to that, um, almost every interaction we had, would end in friction, sort of. It would be a bit bumpy. But once those different rules, that different way of thinking was in place, um, it just, it made life just a bit easier. 	
Difference leading to tensions in relationships	313			Not what she wanted. Clash of styles.
Need for understanding	314			
	315			Changed behaviour
Own beliefs affecting interactions	316			
	317			Understanding what she wants.
Healing of relationships	318			Added a softness to the relationship
	319			Almost every interaction we had would end in friction.
Difference leading to tensions in relationships. Developing understanding.	320			Bit bumpy.
Own beliefs affecting interactions	321			Different way of thinking.

Own beliefs affecting interactions	322	P	<ul style="list-style-type: none"> Not that any of the problems are resolved, are solved, it's just that we're behaving differently about them. Um, I would say for folks not on the spectrum, if you could imagine life as a platform and we're all walking along on an equal footing, the platform is flat for us. For someone like my daughter there's a gradient on this platform. Just to operate normally, she's having to put work in, whereas you and I would think, wouldn't think, our thoughts would be automatic, you know, um, she is having to put in mental energy that you and I just wouldn't even, wouldn't realise we were thinking about. Um, and I think it's only when you realise how much work somebody is having to put in just to stay afloat that you begin to have empathy and sympathy for them, instead of getting angry that they're not performing as well as you think they ought to be. You begin to just feel some sympathy for where they're at. And, and one other thought there that's just, there's a lot of stuff going through my head and, 	Not that any of the problems are resolved. Behaving differently. Trying to understand her experience/
Developing understanding	323			
	324			
	325			Challenge for daughter
	326			
	327			
Developing understanding	328			
	329			Understanding leads to empathy
	330			
	331			
Need for understanding	332			How you think they ought to behave
	333			
	334			
	335	I		
	336	P		
	337	I		
Healing of relationships	338	P	<ul style="list-style-type: none"> Um, so I would say the relationship has softened. Um, in the last 3 years. I can't really imagine where we would be had, had my wife and I not gone through that family relationship counselling thing. It was, it was crucial for us. Ok, I think you've already talked a bit about this, but has your role as a father changed over time, so from infancy to now, and if so, how's it changed? 	The relationship has softened Difficult to imagine.
Life transforming therapy	339			
	340			It was crucial for us.
	341	I		
	342			

Role as father	343	P	<ul style="list-style-type: none"> My role as father from infancy. Well I guess my role has always, in my head. My role has always been as provider. Um, the, the, my wife and daughter stay at home, so I'm the breadwinner, and um, my wife's the carer. And those are functional roles, I suppose. Um, and that's been a constant throughout the whole thing. I think, when, we were going through the counselling session, I remember saying that, I couldn't be the carer, I was really glad that my wife was doing what she was doing, because I couldn't do it. My, my, um, personality, my predisposition, my whole self was just not able to do that. She had to be the carer, I couldn't have done, we couldn't have reversed roles. She couldn't have said, you come into the house for a bit and I'll go out to work. Just wouldn't have happened. So, in that respect, uh, my wife was a much stronger person than me I would say. 	In my head- aware of own perceptions Provider. Wife and daughter stay at home Breadwinner.
Fixed role of mother	344			
	345			
	346			
	347			Couldn't be a carer.
Fixed role of mother	348			
	349			Couldn't have reversed roles
	350			
Coping through avoidance	351			
	352			Views wife as stronger. What does strength mean to him.
	353		P	
	354			Emotionally collapsing Different reactions
	355			
	356			
	357			Unable to function
Struggle and Emotional distress	358		P	
	359			Unable to function
	360			
	361			Impact at work
	362			Mood
Coping through avoidance	363			Thought that work was a haven from home. Coping through avoidance.
	364			To get away

Coping through avoidance	365		issues at home, um, and I, I thought I could do that, I thought I could separate work	Thought could separate.
Not understanding self	366		and home life. Uh, couldn't do it. But all the stuff going on inside my head, just kind	
	367		of spilled out. Work too. Um, so I just, to try and answer your question then, just a	Can't separate.
	368		consistent, um, bread winner, but I couldn't have been a carer, I really could not have	Breadwinner, but I couldn't have been a carer
Role as father	369		made that switch. Laterally, with the softening of the relationship with my daughter,	Softening of the relationship
Healing of relationships	370		um, I, I think, I've become more of a friend to her. I'd probably describe the	More of a friend.
	371		relationship like that. Um, possibly because, I'm, my, my wife is still, I'd say that my	
Different perceptions	372		wife is too much of a carer now, she is protective of my daughter in areas where I	Let go, switch of protective roles.
Difference leading to tensions in relationships	373		think, just let her make that mistake, just, you know, she might learn from it.	
	374		Whereas my wife would say no, you've got to catch it. You gotta catch it.	Gotta catch it.
Story of changes and progress	375	P	<ul style="list-style-type: none"> Um, so, yeh I would say we've moved from a father situation, to maybe a friend 	Move from father to friend.
	376		situation now.	
	377	I	<ul style="list-style-type: none"> Ok, um, and do you think that being the father of your daughter has impacted on 	
	378		your other roles you have, so you've already mentioned work a bit, but at work, or	
	379		socially, has it impacted on you?	
	380	P	<ul style="list-style-type: none"> yeh, yeh, I'm. Other roles, you mean friendships and? 	
	381	I	<ul style="list-style-type: none"> Yeh, any other roles you might have in life. 	
Distress as a parent to see child struggle	382	P	<ul style="list-style-type: none"> I think the experience of finding someone in your family is autistic, and having to 	Finding someone- unexpected.
	383		help them through that is, was for me such a big deal, that I kind of just closed down	Having to help them through that.
Collapse of exterior world	384		many of the other areas I mean. Um, my friendship group, kind of shrunk, because I	Such a big deal/
	385		wasn't really putting much time into it. Um, um, some of the clubs and groups I was a	Closed down, friendship group shrunk
	386		member of, I just didn't go, cos when I came home at night I'd be absolutely	Lack of time

Distress as a parent to see child struggle	387		knackered, and I had to. Have you ever filled out a, have you ever seen a, an	Tiring
	388		application for a statement?	
	389	I	• No, but I've heard that they're awful.	
	390	P	• Or, or, an application for disability living allowance?	
	391	I	• Again, I've heard that they're not great.	
Struggle and Emotional distress	392	P	• You should, you should take a look, at, at what you are asked as a parent. What you	What you are asked as a parent.
	393		are asked to, to write down about your daughter, or about your offspring. Um, this is	Time involved
	394		not, something you can just jot off and, you know, go down the pub. To, to speak	The terms that are needed
	395		about your daughter in terms, the terms that are needed for a disability living	
	396		allowance application, or a statement or any of that stuff, you have to spell out the	Spell out the bad stuff
Struggle and emotional distress	397		bad stuff, and leave them in no uncertain terms about the effects on that person's	Make them understand
	398		life. It is gruelling. It is absolutely gruelling. If you are going to do it properly, you	Gruelling
	399		know, you write letters, several pages of letters. And you do this, not just for those	
	400		applications, but for the annual reviews that happen at school, you write parental	
	401		reports that feed into that. Each of those takes a chunk of time, and a chunk of	Chunk og time and a chunk of emotional energy.
Collapse of exterior world	402		emotional energy. It is not easy.	Exterior world kind of collapsed.
	403	P	• Um, so, uh, you know I would say my exterior world kind of collapsed. It, the, the, the	Compass came in, boundaries came in
Struggle and emotional distress Coping through avoidance	404		compass came in, the boundaries came in. I was, I was no longer operating in, in as	No longer operating in as large as orbit
	405		large an orbit as I, cos I just wasn't emotionally able to. I had to just come in, bring	Not emotionally able
	406		those boundaries in, and just hole up for a bit. Uh, so, it, it, it impacted almost every	Hole up for a bit. Safety/ protection.
	407		area. Of friendships, um, responsibilities here (work), um, yeh it was a big deal. And I	Impacted on almost every area
	408		mean, my daughter isn't you know as I understand it, as I understand the spectrum,	Understanding the spectrum She's a high functioning

Seeing her strengths	409	I P	<p>you know, she's a high functioning uh, Asperger's person. Um, autism can have, you know she's, what I'm trying to say is, of, of the entire spectrum that I could have had, she's at the good end. Um, so, I, and and it was still a monumental, life changing experience to have to go through. I can't imagine what someone would have to go through to deal with, someone else on a different part of the spectrum.</p> <ul style="list-style-type: none"> • I guess it's different, but challenging, wherever you are on it, in different ways. • I guess, yeh, that's right, that's right. I mean there are benefits actually, um, which I didn't really realise at the time. But, my daughter never lies, we don't get any, she's never lied to us. Um, she doesn't visit stupid internet sites, she doesn't smoke, she doesn't drink, she doesn't do drugs. Um, you know, she is a clean living, intelligent person. You know, I don't think I've actually seen any teenage stuff. Can you believe that, I don't know if that's common with uh, other experiences, but, uh, there you go. So, uh, you know, whilst we've got huge worries about some of the, about her, you know her future, her past, her current situation and her future, we just worry about that stuff all the time. We don't really have worries about whether she's going to get drunk, or, dosed up with drugs, or any of that kind of stuff. Just, not in her nature. I, in fact, she, she made a confession to us, just before Christmas. She wrote, in an email, I've got something I want to confess mum, I've had an alcopop, ha ha ha, because, because there was nothing else, I was trying to get some water or some juice at this, at this party, but there was nothing else, I had to, the only thing I could drink was this alcopop. 	Of the entire spectrum that I could have had.
	410			She's at the good end.
	411			Comparison to others
Story of changes and progress	412			Still a monumental, life changing experience
	413			
	414			
Positioning in relation to others' experiences	415			There are benefits actually
	416			
	417			
Seeing her strengths	418			Important ot be clean living, intelligent
	419			
	420			
Positioning in relation to others' experiences	421			Not seen any 'teenage' stuff
	422			
	423			
Uncertain future	424			Huge worries
	425			
	426			
Seeing her strengths	427			Don't' have to worry about some stuff
	428			
	429			
				Not in her nature- because of ASC?
				Humour about her view of things
				Young- delayed?

Uncertain future	430	P	<ul style="list-style-type: none"> So, when you're dealing with someone like that who really is quite, young I would say in there. I don't know if it will come along later, but, um, and I think because of that. 	Uncertainty Terrible partition separation Now fixed. No lines around this anymore
	431			
	432			
Feeling separate	433		The, this terrible partition separation that I drew here, I think that this is kind of now fixed, there's no, there's no lines around this anymore. I think, we feel, each of us feel like this, part of the family, rather than having groups and alliances and stuff.	Part of the family Rather than having groups and alliances and stuff.
Healing of relationships	434			
	435	I		
	436		<ul style="list-style-type: none"> Um, again, you've already kind of covered parts of this, but can you tell me a bit more about your relationship with your daughter. If there is anything else to say? 	
	437	P		
	438			
Difference leading to tensions in relationships	439		<ul style="list-style-type: none"> Um, anything other than what we've said? Um, well, we could look at, um, because, personality wise, she's closer to her mother, they will naturally spend time together. Um, whereas personality wise she is quite different to me, so you know, if we are going to do leisure things I tend to be off doing one thing and she'll be doing something else, so the. We, we, we don't have us much time together as she would with her mum. For that reason I suppose you could say we're not as close as, as they are. Um, I, I was going to say, I'm not sure I can say that much more about the relationship. 	Personality alike. Don't share interests Time together= closeness
	440			
	441			
Feeling separate	442		<ul style="list-style-type: none"> No, that's fine, you have already said quite a lot in the other bits. 	
	443	I		
	444			
	445	P	<ul style="list-style-type: none"> Yeh, yeh. 	
	446	I		
	447			
Positioning in relation to others' experiences	448	P	<ul style="list-style-type: none"> Um, and,, What do other guys say about the relationship with their offspring? 	Interest in other fathers' experiences.
	449	I		
	450	P		

Healing of relationships	451	I	<ul style="list-style-type: none"> I think probably the things you've already said, but as part of the other questions you've already talked about it, Ok And, do you think being a parent to, and living with your daughter, has had an impact on your relationship with your wife. So you've talked a bit about, kind of, the partitioning and, You've heard it, it was, it was, it was bad. How about now, so you've said it kind of feels more.. I think it's healed. I think there's been a healing there. Um, we have had to forgive, we've had to acknowledge stuff, and apply a good chunk of forgiveness. But I mean, that's that's, marriage for you, you know, there's nothing, there's nothing unique about that, um. I, but that, that healing process was necessary, and takes a chunk of time, um, um, it's a recalibration. You know what, again, what you think you have with someone, suddenly you get to a point where you realise that's not what you've got actually, you've got somebody whose upset because you're not behaving in a reasonable, a reasonable way or. I, have, have you come upon the idea of gathering clouds? Where, say, you'll do something irritating and nobody will say anything, and then it'll happen again, and we won't talk about it, eventually, you know, eventually the cloud will part and it will start raining. It might not be anything big, it might be something really trivial, but suddenly you've got a storm on your hands and it's just, it's all just coming out. 	<p>It was bad Healed. There's been a healing there. We have had to forgive..</p> <p>That's marriage for you- normal</p> <p>Time involved in healing.</p> <p>Mirrors feelings about diagnosis- loss.</p> <p>Wasn't acting reasonably?</p> <p>Gathering clouds</p> <p>Storm</p> <p>Prior to camH</p>
	452			
	453	P		
	454	I		
	455			
	456			
	457	P		
	458	I		
	459	P		
	460			
Positioning in relation to others' experiences	461			
Healing of relationships	462			
Difference leading to tensions in relationships	463			
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	465			
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	471			

Difference leading to tensions in relationships	472	P	<ul style="list-style-type: none"> SO, so I think prior to the camh counselling, my wife and I had been building up some storm clouds. It was very difficult to talk about it. In fact I think that's what camh kind of did for us, they, they gave us a structure in which to diffuse some of that stuff. 	Building storm clouds in marriage camH gave structure to talk
Life transforming therapy	473			
Developing understanding	474			
Healing of relationships	475		Um, and slowly we began to unravel the clouds. Took a long time, like I say I think it	Time
Story of changes and progress	476		was 4 years, um, and as I say I think that was, we stopped seeing them about 2 or 3	Stronger for it.
	477		years ago. I would say the relationship with my wife now is really really good. We are	Strength in partnership
Healing of relationships	478		certainly stronger for it, we're partners now, in a way that, um, we were almost	Adversaries
Strength as a team	479		adversaries before. I, I would see, I would see my wife and daughter's relationship,	Left out, separate. Jealous?
	480		and think, crumbs, that looks really quite nice, I wish I had one of those. I felt really	
Feeling separate	481		quite separate and distant from it all. But a, so it's taken us all of that time to really	Needed to get to a level of understanding
Need for understanding	482		get back, back to a level of understanding again.	
	483	I	<ul style="list-style-type: none"> mm 	Good relationship, good marriage
	484	P	<ul style="list-style-type: none"> So I'd say I have a good relationship, I've got a good marriage, I know that. And, and 	Corners have been knocked off us
Positioning in relation to others' experiences	485		in some, bizarre way I would say that the corners have been knocked off us, that	Normal experience of marriage.
Story of changes and progress	486		again, that's what marriage is about, it does knock corners off you. Um, and we are	Stronger from having come through this
	487		stronger from having come through this, um, this experience.	
	488	I	<ul style="list-style-type: none"> Mm, ok. And do you think that being a parent to, and living with your daughter had 	
	489		an impact on your relationship with other members of your family, I don't know,	
	490		obviously they're quite far away, but?	Trying to explain to others
Need for understanding	491	P	<ul style="list-style-type: none"> Yeh, it did, well my folks are in Cardiff, and um, again, trying to explain to them, that 	They don't know was Asperger's was
	492		their granddaughter has Asperger's, they don't know what Asperger's was, they don't	Lack of understanding
	493		know what autism was. They'd heard the word, but never really, um. And I don't	All three of us

Developing understanding Need for understanding	494	P	<p>think they have ever, whilst my wife and I, in fact, whilst my wife and my daughter and I, all three of us, have made quite a journey, to a point where we're understanding what's going on, my folks never did. They, just never really got it. I'd try and explain it, but every time, I went to visit them, and they brought the subject up, it was clear that they never really got it.</p> <ul style="list-style-type: none"> Um, and you, you kind of need. What was I going to say? If you, if you're going through a difficult patch, and somebody doesn't understand what you're going through, it, kind of puts a bit of a barrier in there. So, in that regard it did affect my relationship with my folks. Um, cos they just never really understood. I think laterally they, they did, they began to ask questions, like, um, how's your marriage? Ha ha ha. What affect is this having on your marriage? You know, my dad asked me that question about 6 years after we'd started talking to him about my daughter's Asperger's. So, um, yeh, he, he finally got the idea that this might be a big deal. Yeh, so yeh it did affect that. 	<p>Made quite a journey Journey to understanding Trying to explain</p>
	495			
	496			
	497			
	498			
Difference leading to tensions in relationships	499	P	<ul style="list-style-type: none"> Um, and you, you kind of need. What was I going to say? If you, if you're going through a difficult patch, and somebody doesn't understand what you're going through, it, kind of puts a bit of a barrier in there. So, in that regard it did affect my relationship with my folks. Um, cos they just never really understood. I think laterally they, they did, they began to ask questions, like, um, how's your marriage? Ha ha ha. What affect is this having on your marriage? You know, my dad asked me that question about 6 years after we'd started talking to him about my daughter's Asperger's. So, um, yeh, he, he finally got the idea that this might be a big deal. Yeh, so yeh it did affect that. 	Barrier if no understanding
	500			
	501			
Feeling separate	502	P	<ul style="list-style-type: none"> Um, and you, you kind of need. What was I going to say? If you, if you're going through a difficult patch, and somebody doesn't understand what you're going through, it, kind of puts a bit of a barrier in there. So, in that regard it did affect my relationship with my folks. Um, cos they just never really understood. I think laterally they, they did, they began to ask questions, like, um, how's your marriage? Ha ha ha. What affect is this having on your marriage? You know, my dad asked me that question about 6 years after we'd started talking to him about my daughter's Asperger's. So, um, yeh, he, he finally got the idea that this might be a big deal. Yeh, so yeh it did affect that. 	<p>Never really understood Not really funny</p>
	503			
	504			
Developing understanding	505	I	<ul style="list-style-type: none"> And you said a bit earlier about the impact it had on your social circle, so that really 	Time to get to understanding
Impact of Asperger's	506			
Developing understanding	507			
Own beliefs affecting interactions	508	P	<ul style="list-style-type: none"> It collapsed in yeh 	Finally got the idea Big deal
	509			
	510			
	511	P	<ul style="list-style-type: none"> Has there been any change in that over time, is that stayed that way or? 	Haven't really managed to break out again
	512			
Struggle and emotional distress	513	P	<ul style="list-style-type: none"> It has kind of stayed that way, yeh. I haven't really managed to, to break out again. Um, I don't know, I don't know if I can say why, it's just. I suppose you get into a habit of, just whatever's comfortable. Um, you know I used to be out about 4, 3 or 4 nights a week doing various things, and now I don't think I go out at all during the week, in the evenings. Um, there's just too much, there's too much to do, um. So, so, yeh, I've 	<p>Get into a habit of just whatever's comfortable WOuldn't have been at home very much Too much to do</p>
	514			
	515			

Story of changes and progress	516		never really got back to where I was before. It's just changed the direction of, of	Changed the direction of social and recreational
	517		social and recreational stuff. It's just embarked us in a new direction. In fact, what I	stuff. Embarked us in a new direction
	518		do, what I do at weekends, is I, I look up google and I look at Asperger's charities,	Look up google and I look at Aspergers charities
	519		and I find, a charity, and I look at their web-page, and I find that (researcher) is going	Looking up information
	520		to go and talk to them, and it's all about fathers, so you know. That seems to be	
	521		where I'm directing my energy now.	Can only direct energy in one direction at a time?
	522	I	<ul style="list-style-type: none"> That information and knowledge side sounds quite important? 	
Positioning in relation to others' experiences.	523	P	<ul style="list-style-type: none"> It is, but I, I just don't want anybody else to have to go through the experience that I 	Importance of helping others
Services under-resourced	524		did. I'd really like the support services to be better, better equipped. Um, it's all	I'd really like the support services to be better, better equipped
	525		about money I suppose. And do you know what, camh have reduced their services, I	
	526		don't know what the equivalent is in other counties,	
	527	I	<ul style="list-style-type: none"> Um, yeh camh tends to, it child and adolescent mental health 	
Services under-resourced	528	P	<ul style="list-style-type: none"> That's it, yeh, they, they just don't have the funds to do what they need to do. It's 	Under resourced
	529		just, it's crazy, because. You know, I, I, I would probably say that my wife and I would	
Life transforming therapy	530		be divorced if it wasn't for their help. For the family relational therapy that we got.	Saved marriage
	531		So, you know, you wanna tot up the cost of the divorce, the family break up, you	
	532		know there must be a cost to the family, but there must also be a cost to the, to the	
Good support lets life flourish	533		country. And you compare that with, you know, a few counselling sessions with	
	534		camh. If you can fix it before it's broken, it's a lot better.	If you can fix it before it's broken, it's a lot better
	535	I	<ul style="list-style-type: none"> Yep, if only they thought that way. 	
	536	P	<ul style="list-style-type: none"> Yeh, well, they, they need to. 	

Struggle and emotional distress Feeling let down by services	537	I	<ul style="list-style-type: none"> That kind of leads on to, and again you've talked a bit about it, but can you tell me about your experiences of accessing support for your daughter? It sounds like they've been mixed. 	It's been extremely difficult They failed us, they failed us...
	538			
	539			
	540	P		
	541			
	542			
	543			
	544			
	545			
	546			
Positioning in relation to others' experiences	547		<ul style="list-style-type: none"> Um, well, like I've said it's been extremely difficult, the support services have, I would say they failed us. I would say they failed us at the school, I'd say they failed us at, in as much as when my daughter went to see the support services at camh, they missed it, they missed it. And they said stuff like, she's not bad enough to, to have therapy from us. Um, which is, I think what they meant was, you know, we've got kids here who are much worse, and that is true, I can imagine that is true. But, there is something severely broken about our system, which say that a child who is hitting herself isn't bad enough. 	They missed it, they missed it She's not bad enough
Feeling let down by services	548	I		Something severely broken about our system
	549			
	550	P		
	551			
	552			
	553			
	554			
	555			
	556			
	557			
Need to badger to get support			<ul style="list-style-type: none"> And did they offer any other, avenue for you to go down? So they said they couldn't do anything but, was there. 	Ultimately when we pressed. Need to press
Need to badger to get support				Had to push all the time
Struggle and emotional distress Feeling let down by services			<ul style="list-style-type: none"> Only, only when, well ultimately when we pressed, if, if, we had said, if we had said, oh that's a shame and just went off, you know, nobody would have said, hang on a minute, there's one or two other things we could do here. Um, it, it was, we had to push all the time, we had to, when we got no for an answer, we had to find some alternative ways around that. Um, and eventually, I suspect, just because we were a pain in the butt, eventually we got, I think what we needed. Um, but it was not easy, it was not easy. The services and the professionals who ought to have known and recognised symptoms and conditions and known where to look were not there. 	Alternatives Need to be a pain in the butt to get support It was not easy, it was not easy
				Ought to have known

Seeking support	558	P	<ul style="list-style-type: none"> As I say, we paid, we went to a private, uh, child psychiatrist. Um, cost 1500 pounds, um, and that was, that was the key that unlocked the flood gates, without that diagnosis, we would have got nothing. So, so another concern there, is, you know, I happen to be blessed to be able to afford to just do that. Not everyone can just shell out that kind of money, to get a diagnosis. Um, so, my heart goes out to those folks that can't. 	<p>The key that unlocked the floodgates</p> <p>Without that diagnosis we have got nothing</p>
Good support lets life flourish	559			
Diagnosis as helpful	560			
	561			
Positioning in relation to others' experiences	562			Concern for others
	563			
	564	I	<ul style="list-style-type: none"> Um, and can you tell me about your experiences of accessing support for yourself? I don't know if you've looked anywhere other than the camh family stuff? 	
	565			
Struggle and emotional distress	566	P	<ul style="list-style-type: none"> Do you remember I said I didn't think I was depressed, when all that kicked off? Because of that I don't think I was looking. Um, I don't like going to doctors, I certainly don't like going to head doctors. Um, that was, that was my thinking then. 	I don't think I was looking
Story of changes and progress	567			Change in thinking
	568			
Life transforming therapy	569		<ul style="list-style-type: none"> I've, I've completely come around actually, I, I think talking therapies are fantastic, if you can get the right person. Um, if you can get the right person. Um, so, at the time that I needed that support it was kind of my wife that was pushing, and, and, I, Organising it. I kind of just went along with her. Um, and we just happened to land on our feet there. 	Importance of the right person
	570			
	571			Organising
	572			
	573			
Seeking support	574	P	<ul style="list-style-type: none"> I didn't actually take the initiative and go looking for it, um, er, until, actually that's not strictly true. I didn't go looking for it within camh, I think I did uh, try one or two counselling, uh private counselling, uh places. But again, I didn't find anything that suited. Um, I didn't find anything that suited. That's maybe a, personal thing, you know, it's all about how well you can get on with that, with your counsellor, how well your counsellor can open you up, to, to new ideas and to, to hold up a mirror and let 	Not suitable
	575			
	576			
	577			
	578			Right person
Needing understanding	579			Understanding, and helping you understand

Services under-resourced	580	I P	you see how you're thinking. Um, maybe offer one or two different ways of thinking.	
	581		SO I, I did try one or two other avenues, but found that they were not suitable.	
	582		<ul style="list-style-type: none"> Um, and how do you feel about your daughter's future, at the moment? 	
Feeling let down by services	583		<ul style="list-style-type: none"> Hah, that's a good question, Um, from the earliest experiences at school, we were 	There's no money +++ No, No, No +++ By gods mercy
	584		told, there's no money, can we have a TA, there's no money, there's no resources,	Importance of diagnosis
	585		um, can we apply for a statement? You won't get a look in. Um, so we've had no no	Muddled through
Bumblng through	586		no no all along the way, and yet, somehow, by god's mercy, we have got a	Delivered good a levels
Good support lets life flourish	587		statement, we got a diagnosis, we got a statement, we, uh, muddled through school,	
Seeing her strengths	588		we put her into a cracking sixth form that delivered, that, that, just, she flourished at	
	589		it, and got a levels she needed and got to University/town, and got support at	For all the no, no, no, no we somehow have got
	590		University/town, um, so for all the no no no no no, we somehow have got through it	through it
Story of changes and progress	591		to a place where she is getting a good university education. And I kind of think,	Future is uncertain
	592		although the future is uncertain. Extremely uncertain. I kind of think, we will get	Somehow or other we will get through this, by
	593		through this. Somehow or other we will get through this, by god's grace.	god's grace
	594	P	<ul style="list-style-type: none"> Um, if, if you asked me would I employ my daughter? I wouldn't, her organisational 	Wouldn't fit- wouldn't employ daughter
	595		skills are such that she, she wouldn't fit, if you go downstairs to our, to our office, it's	Importance of organisation
	596		full of highly educated highly organised people. Uh her organisation lets her down I	She would struggle
Impact of Asperger's	597		think. She would struggle, she would struggle to get to a job, on time every day. Um,	
	598		she would struggle to, this is currently, if you were to take her out of university and	She couldn't do that
	599		say, off you go, get a job, make it work. She couldn't do that, she couldn't care for	
	600		herself and organise herself. So if we look at the picture right now, it's I'd say she	
	601		wouldn't get a, she wouldn't get a job, but I think we're not looking at the picture	

Story of changes and progress	602		right now, we're looking at a journey, and there has been progress. If I remember	We're looking at a journey, and there has been progress
	603		how she was when she was in primary, if I remember how she was in secondary,	Remember her development
	604		remember her in sixth form, and look at her now, she is making progress. There is	Progress
Good support lets life flourish	605		still development there, and with appropriate support, she's doing OK.	With appropriate support, she's doing OK.
Uncertain future	606	P	<ul style="list-style-type: none"> I think she, with a fair wind, she'll make it. That's almost a statement of faith rather than a, a, statement of knowledge. 	With a fair wind, she'll make it.
	607			Statement of faith
	608	I	<ul style="list-style-type: none"> Have you got any other hopes, and/or fears for her future? 	Knowledge is important
Impact of Asperger's	609	P	<ul style="list-style-type: none"> Oh, yeh, I mean, because she struggles with organisation, handling finances is a real headache for her. You know she could go overdrawn and not even think about it. Get 	Practicalities of finance
Distress as a parent to see child struggle	610		into all sorts of trouble.	Trouble
	611			
	612	I	<ul style="list-style-type: none"> IS that something you help her with at the moment? 	
Uncertain future	613	P	<ul style="list-style-type: none"> Yeh. Um, so financially I would say, you know, if she. I guess it's because you can't 	You can't see the next step ahead, you can't see
	614		see the next step ahead. You can't see beyond the next step ahead. And because you	Uncertainty
	615		can't see beyond the next step ahead, you can't see, right now we're looking at	
	616		university. You can't see what the jobs going to be at the end of that. You can't see	
	617		where it's going to be. You can't see whether it's going to involve moving away from	Independence
	618		home, whether it's going to involve her own accommodation, her own transport, all	
Uncertain future	619		the stuff you would expect a young person to handle. But, but you can't see her	
	620		doing that right now.	How am I going to make sure that my daughter's
Uncertain future	621	P	<ul style="list-style-type: none"> So, um, and you know my dad's just died three months ago, I, and I'm thinking, well, 	OK? (when he dies)
Role as father	622		if I go, how am I going to make sure that my daughters ok? Um, because, I'm going	
	623		through the probate process right now, and it's a nightmare. Um, I can't imagine	

Distress as a parent to see child struggle	624	P	<p>asking my daughter to do that for me. You know, my dad, my dad was pretty well organised, he left his affairs in order, and even so it's a. You, it's just because you're dealing with something that you only do once or twice in a lifetime, you know. Um, so you got to learn fast on your feet.</p> <ul style="list-style-type: none"> But I couldn't imagine my daughter having to deal with that, so. Somehow, somehow, we've got to think of ways to help support her disability beyond the university, if, if she needs it. And I really hope and pray that she just won't need it. 	<p>Somehow, somehow Help support her disability</p>
	625			
	626			
	627			
	628			
	629			
	630			
	631			
	632			
	633			
Importance of independence Seeking support	634	I	<ul style="list-style-type: none"> Um, and just a very general one. Is there anything else you'd like to share, do you have anything that it would be really important to think about, that I haven't asked? 	<p>Hope and pray</p>
	635			
	636			
	637			
	638			
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	640			
	641			
	642			
	643			
Positioning in relation to others' experiences	644	P	<ul style="list-style-type: none"> What have you not asked, or what have I not said? If it's about fathers, and if other fathers are in any way similar to me, um, I would just, again I have to emphasise this, and it's get some help and talk about what's going on inside your head, that is the, 	<p>Reality Difficult not to have answers?</p>
Advice to other fathers		I	<ul style="list-style-type: none"> Ok, um, and what has it been like talking about your experiences here today? 	<p>If other fathers are in any way similar to me</p>
Need for understanding				<p>Get some help and talk</p>
				<p>Ideas about other dads</p>
				<p>Need to break through Dark tunnel</p>
				<p>Busy</p>

Struggle and Emotional suffering Story of changes and progress and progress	645	P	<ul style="list-style-type: none"> What's it been like? Ah, it's been very pleasant, it's the calmest 2 hours I've had in my day. Um, sorry can you just, is that from an emotional perspective, or? However, you want to take it really, or have I enjoyed your company? He he, I guess it's different for different people when they're actually talking about these things, so I'm just, yeh, probably emotionally, what's it been like? Its fine yeh, fine, I mean I think, you may have judged that a lot of the emotional stuff for me came out 2 or 3 years ago, that's all past now, but I tell you what I couldn't. If you'd, if you'd come to me 4 years ago, I would have had a 16 year old Asperger's daughter, just coming up to the, what is the O'levels, um GCSES? You know, going through that phase. I couldn't have done this interview. I could not have done it. Um, certainly not in such calm, considered um, ways. Um, I think I would have, I probably would have just broke down, you know. Tears and stuff like that. But, as I say, I think that was a bereavement process, and we do get past bereavements, and onto a better footing. Um, so, you know I can imagine there are other guys who you're seeing, uh. I would find that quite difficult I think, had I not gone through the, had the counselling, the family therapy that we did. I don't think I could have given this interview, I just don't think it would have happened. I certainly wouldn't have contacted you and said, hey come along I'm interested in this, come over and let's talk. Wouldn't have happened. So I'd be very interested to know how the other guys you've seen, how did they answer that question. 	<p>Emotional stuff in the past</p> <p>Change in self</p> <p>Couldn't have spoken about it</p> <p>Break down, tears and stuff= bad?</p> <p>Bereavement</p> <p>We do get past bereavements and onto better footing</p> <p>Other fathers</p> <p>Interest in others</p>
	646			
	647	I		
	648	P		
	649	I		
	650			
	651	P		
	652			
	653			
	654			
Own beliefs affecting interactions Struggle and emotional suffering Diagnosis as bereavement	655	I		
	656	P		
	657			
	658			
	659			
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	662			
	663			
	664			
Story of changes and progress Positioning in relation to others' experiences	665			
	666			
Life transforming therapy				
Positioning in relation to others' experiences				

Story of changes and progress	667	I	<ul style="list-style-type: none"> Um, it, it's been a mix again. Some people saying its fine, some people saying it's been nice to talk about it, so it's been a mix. 	<p>Cope by ignoring</p> <p>Linked in with others.</p>
	668			
	669	P	<ul style="list-style-type: none"> Well all my talking sort of got done then. SO what I'm reporting to you now isn't news to me. 	
Coping through avoidance	670			
	671	I	<ul style="list-style-type: none"> yep 	
	672	P	<ul style="list-style-type: none"> But some of those, some of those questions that you've got there, can, just help to make you think about stuff that you tend to want to push down and ignore. Um, yeh. 	
	673			
	674	I	<ul style="list-style-type: none"> Yeh, and my final question, er, will you talk to anyone else about this interview later, and what you've said? 	
	675			
	676	P	<ul style="list-style-type: none"> I'll tell my wife about it when I get home, she's interested. I think I'll, all also email the lady at the charity, and let her know that we've met. I would actually like to go and meet with her, um, but it's just a wee bit far for getting there from University/town at the end of the day. Um, so I, I won't come and, it's next week that you're going over there isn't it, yeh I won't come to that meeting, but I would just like to make a trip over there at some stage, maybe in the spring or the summer. When it's going to be a bit easier. 	
	677			
	678			
	679			
	680			
	681			
	682			
	683	P	<ul style="list-style-type: none"> Because it sounds to me like what she does there is pretty useful. She's giving the kind of counselling services that I think may be required. 	
	684			
	685	I	<ul style="list-style-type: none"> yeh 	
	686	P	<ul style="list-style-type: none"> For parents of Asperger's and autistic folks. 	

APPENDIX I. List of emerging themes for 'Charles'

List of Emerging themes

Story of changes and progress
Impact of Asperger's
Developing understanding
Need for understanding
Distress as a parent to see child struggle
Different perceptions
Bumbling through
Seeking support
Feeling let down by services
Services under-resourced
Seeing her strengths
Diagnosis as helpful
Importance of independence
Need to badger to get support
Good support lets life flourish
Difference leading to tensions in relationships
Diagnosis as bereavement
Feeling separate
Struggle and emotional distress
Not understanding self
Positioning in relation to others' experiences
Coping through avoidance
Role as father
Strength as a team
Own beliefs affecting interactions
Life transforming family therapy
Advice to other fathers
Fixed role of mother
Healing of relationships
Collapse of exterior world
Uncertain future

APPENDIX J. Clustered themes for Charles

Clustered themes

Tensions and Strengths in Relationships

Collapse of exterior world
Healing of relationships
Positioning in relation to others' experiences
Strength as a team
Difference leading to tensions in relationships
Distress as a parent to see child struggle
Feeling separate
Role as father
Advice to other fathers
Fixed role of mother
Own beliefs affecting interactions

Variable experience of support services

Feeling let down by services
Life transforming family therapy
Need to badger to get support
Seeking support
Services under-resourced
Good support lets life flourish

Importance of Understanding

Developing understanding
Differing perceptions
Need for understanding
Uncertain future
Not understanding self
Bumbling through

Difficult relationship to daughter's diagnosis of Asperger's

Importance of independence
Story of changes and progress
Impact of Asperger's
Seeing her strengths
Diagnosis as helpful
Diagnosis as bereavement
Struggle and emotional distress
Coping through avoidance

APPENDIX K. Table of themes with quotes from text for Charles

	Line	Quote
Tensions and Strengths in Relationships		
Collapse of exterior world	403-405	you know I would say my exterior world kind of collapsed. It, the, the, the compass came in, the boundaries came in. I was, I was no longer operating in, in as large an orbit
Healing of relationships	459-460	I think it's healed. I think there's been a healing there. Um, we have had to forgive, we've had to acknowledge stuff, and apply a good chunk of forgiveness
Positioning in relation to others' experiences	144-145	And the way that I dealt with that, probably in common with most men,
Strength as a team	477-478	We are certainly stronger for it, we're partners now,
Difference leading to tensions in relationships	159-160	Whereas when I tried to interact with my daughter, there was tension, there were tensions there.
Distress as a parent to see child struggle	30-31	which is really quite distressing when your child starts to do stuff like that.
Feeling separate	154-156	and I saw a strong bond of relationship between my wife and my daughter, and I saw myself as separate to that. I saw them as a team and me as separate
Role as father	271-272	I'm thinking as a father I've got to bring this person on, and, and give her the skills
Advice to other fathers	190-193	I would be keen to just get the message out to other men who are in the same position, that you can't just go out on your own, on motorbikes or runs round forest, you need to talk about this stuff.
Fixed role of mother	348-349	I was really glad that my wife was doing what she was doing, because I couldn't do it
Own beliefs affecting interactions	183-184	Just a better way, a better way to be. Instead of having a crusade, to make my daughter independent, I needed to just work with who I had
Variable experience of Support Services		
Feeling let down by services	98-99	lots of really good sounds coming out, but the delivery was poor. Didn't happen, didn't work
Life transforming family therapy	186-188	we saw a family relationship therapist at Camh, it was the most, life transforming experience I think I've had. And I, I, wonder what I would have done without that actually
Need to badger to get support	96-97	we were perpetually badgering the school. Finding out, how's this going, what's happening, whys she not getting support, what's going on.

Seeking support	42-44	we tried hard to, we went through the medical, a medical route, the surgery to be referred to a specialist to try and get a diagnosis of some kind.
Services under-resourced	528-529	they just don't have the funds to do what they need to do. It's just, it's crazy,
Good support lets life flourish	112	With support her academic stuff is, life can flourish.
Importance of understanding		
Developing understanding	320-321	But once those different rules, that different way of thinking was in place, um, it just, it made life just a bit easier.
Differing perceptions	53-55	you'd be, in common with most of the rest of the world, you'd say that's a lovely young woman, competent, articulate, intelligent, what's the problem, you know, what's the problem?
Need for understanding	180-181	that was the start of my recovery, because I, that guy helped to to, helped me to understand why I was thinking the way I was thinking
Uncertain future	613-614	I guess it's because you can't see the next step ahead.
Not understanding self	139-140	my experience of me, is that I don't really understand my emotional responses very well
Bumbling through	23	we kind of bumbled through it I guess
Difficult relationship to daughter's diagnosis of Asperger's		
Importance of independence	305-307	The crusade as we used to call it, this, this um, insatiable, unquenchable desire to make my daughter independent,
Story of changes and progress	602-603	we're looking at a journey, and there has been progress. If I remember how she was when she was in primary
Impact of Asperger's	17-18	she found school tremendously difficult, because her organisation is really quite impaired
Seeing her strengths	102-103	so the academic ability is unquestionable, she has all the academics you could ever hope for.
Diagnosis as helpful	128-129	the diagnosis helped her. Suddenly she was, she was, freed of, of self-doubt, she understood
Diagnosis as bereavement	123-124	I'd possibly describe it as the worst thing that's happened to me in my life so far. It was, it was like a bereavement
Struggle and emotional distress	141-142	I think I was depressed, now. I think I can understand, and my wife I think, certainly understood that I was depressed
Coping through avoidance	144-145	And the way that I dealt with that, probably in common with most men, was by, by separating myself from the problem.

APPENDIX L. Clustered themes for all participants

Peter	Ben	Sam	Henry	Andrew	Charles	Mike
<p>Son's experience Son's ways of coping Clingy/demanding Impact of mental health difficulties Difficulties at key transitions in life Our worlds overlap, but his bubble is his own territory</p> <p>Relationship with son Frustration Worry Pride in achievement Such hard work that you're going to start not bothering 'Life is fun with Asperger's' Roles changing over time Calming down Supporting and Rescuing Everything we do we have to think about him Doing whatever is necessary Work as get out clause Flexibility of work vital Practical vs emotional Impact of health issues on parenting Planning for future</p> <p>About Asperger's 'Typical' Asperger's</p>	<p>Relationship with son Helped by learning how to respond. Frustration and anger Find pathways in background, can't get too interested. Did have a role, less clear now. Being blamed Ups and downs- good times and terrible years Doing something vs no spark of interest. Clever boy Planning for future Need to contain and keep safe, terror if not contained Not talking about things in front of son Volatile marriage- resolve to make better Son copes through escape</p> <p>Perceptions of services Police are the only help you ever get. Feeling that professionals are out of their depth or not interested. Feeling let down. Not in control.</p>	<p>Developing understanding and relationship Trying to understand Diagnosis as road map for what needed doing Not worth thinking about how things could be different it's just how life is Delightfully different, wouldn't have him any other way Great bond between us- a lot in common</p> <p>Support Inconsistency in social services Cross-supportive Pushing for action and support Best place for son is with others like him Private journey</p> <p>Parental responsibility Factor him into everything we do He's still in our care in many, many senses of the word. Life has changed, role has changed</p>	<p>Impact and Reactions to difficulties It was terrible/ awful to see suffering Cope by just getting on with things. Learning and relearning different approaches Frustration and friction because she feels this, but I feel that. Guilt Feeling responsible Opens up a lot of feelings for us. Plunges you back into that previous time Makes you look at yourself Carer role impinges on life Difficult, traumatic time All events have shaped things Concern for siblings Before and after diagnosis</p> <p>Developing an Understanding daughter Trying to make sense of what has happened. Understanding her emotional regulation. There's no credit in the bank She's tried and it still goes wrong She just blocks it out</p>	<p>Variable support Not a lot of support around People don't tend to think of fathers as particularly in need Frustration of things not working as they should Schools have been impressively good Need to know and understand about Don</p> <p>Relationship with Son Distress to think of others tormenting Don because he's different Can talk about only certain things Advice Finding it difficult to deal with Don I still feel responsible for him, but he doesn't think I am Making sure Don is OK in the future Equality vs hierarchy Comparison of sons Several years behind Fairly successful Unreasonable fuss-disapproval and shame Been less of a problem than we'd been told</p>	<p>Tensions and Strengths in Relationships Collapse of exterior world Healing of relationships Positioning in relation to others' experiences Strength as a team Difference leading to tensions in relationships Distress as a parent to see child struggle Feeling separate Role as father Advice to other fathers Fixed role of mother Own beliefs affecting interactions</p> <p>Variable experience of support services Feeling let down by services Life transforming family therapy Need to badger to get support Seeking support Services under-resourced Good support lets life flourish</p> <p>Importance of Understanding</p>	<p>Strength of relationships Happy close family Very strong father- daughter relationship Impact as a family rather than individual Fortunate that wife takes brunt People sympathetic Spend more time together as she got older Positive asset</p> <p>'Dealing with her' Keep her on an even keel Impact in marginal ways Whole life modified and adjusted It's the way we all deal with her that matters It's difficult to make her happy, very easy to make her unhappy Aim for a reasonably happy and fulfilled life Fear of anxiety tipping over into depression</p> <p>Support Services getting it wrong Not needed support for self. Should I have done something differently? Monitored development</p>

<p>Visible vs invisible disability Would earlier diagnosis have been better?</p> <p>Variable experience of support structures Funding problems Working out how to support Disappointed in support Better support- better outcome Cut off from others as others couldn't cope Can only cope if understand</p>	<p>Others too different to be helpful but developed commonality. Seeking help, but not able to hook in.</p> <p>Developing an understanding We knew vs we didn't realise/ Didn't know that there were clearly problems What do we do? Always thought it's just a matter of time, but we might be in for the long run Depression- it's a real big deal.</p>	<p>Protect from traumas of the world. Get organised for future Testing and painful to see child upset Roles</p> <p>Coping Eldest's difficulties overshadow Men accept and look for a solution Frustration Coped as best we could</p>	<p>Once she'd had a diagnosis things made sense The ability to provoke that intense emotion. She has done really well Want to stop things tipping her into crisis</p> <p>Variable experience of support structures Excellent support Support is lacking Need the right knowledge and understanding in order to help Open-minded people supportive, judgemental people hurtful. Reliance on each other</p>	<p>Things have improved Limited what we could do Not a visible problem</p> <p>Parenting alongside partner Not the best father as working a lot Dads were expected to earn the money and mothers were expected to stay at home Disagree on how we ought to deal with him Strained the relationship That's a matter of viewpoint</p>	<p>Developing understanding Differing perceptions Need for understanding Uncertain future Not understanding self Bumbling through</p> <p>Difficult relationship to daughter's diagnosis of Asperger's Importance of independence Story of changes and progress Impact of Asperger's Seeing her strengths Diagnosis as helpful Diagnosis as bereavement Struggle and emotional distress Coping through avoidance</p>	<p>We're parents who have no experience of this sort of thing Get involved Nobody told us All through school she was unhappy Good support</p> <p>Relationship to Asperger's Typical Asperger's Realised something wasn't quite as it should have been Stigma of label. Better to not feel she's different Learning to be rational</p>
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APPENDIX M. Individual super-ordinate themes for all interviews

Individual superordinate themes for all interviews

Peter	Ben	Sam	Henry	Andrew	Charles	Mike
<ul style="list-style-type: none"> • Son's experience • Relationship with son • About Asperger's • Variable experience of support structures 	<ul style="list-style-type: none"> • Relationship with son • Perceptions of services • Developing an understanding 	<ul style="list-style-type: none"> • Developing understanding and relationship • Support • Parental responsibility • Coping 	<ul style="list-style-type: none"> • Impact and Reactions to difficulties • Developing an Understanding daughter • Variable experience of support structures 	<ul style="list-style-type: none"> • Variable support • Relationship with Son • Parenting alongside partner 	<ul style="list-style-type: none"> • Tensions and Strengths in Relationships • Variable experience of support services • Importance of Understanding • Difficult relationship to daughter's diagnosis of Asperger's 	<ul style="list-style-type: none"> • Strength of relationships • 'Dealing with her' • Support • Relationship to Asperger's

APPENDIX N. Super-ordinate and subordinate group themes, with example quotes from all transcripts.

The changing role but constant responsibility of being a 'Father'	1 Peter	2 Ben	3 Sam	4 Henry	5 Andrew	6 Charles	7 Mike
<i>I would have done whatever was necessary</i>	833-834 So, everything that we do, centres around Simon, 615-616 I would have done whatever was necessary	867-868 Lately I haven't been feeling quite, I'm beginning to feel that we might be in for the long run.	305-307 The whole time we have to be thinking, how does Mark fit into this arrangement or that arrangement, he's still in our care, in many, many senses of the word.	436-437 It's the pressure really of giving her what she needs and supporting her.	295 I still feel responsible for him, but he doesn't think I am. 558-559 If you have children you take on a big responsibility but you don't know what it's going to be like until you get there.	305-307 The crusade we used to call it, this, this um, insatiable unquenchable desire to make my daughter independent.	96-97 Your whole life is modified and adjusted by the fact that she's there and the way she is. 123-124 As long as I've always got her best interests at heart.
<i>Life has changed, role has changed: we're looking at a journey</i>	262- 264 That's where I've come in and sort of, pinned him down practically, that's when he was younger, um, nowadays..	427-429 You can't even take the horse to water, you know, I mean, it, its just, you know, I was, I was absolutely Machiavellian.	263-264 What it was like when he was a youngster, um, he was, it was tempestuous. 287-288 Obviously my life has changed because that is no longer necessary.	27-28 So I think it's time to do something, not for myself, and so that's why I've started the course. 307-309 Getting some perspective. Which I used to think that I had. So It's completely upended all my, feelings about myself as a parent. You know, really changed everything.	210-211 So the answer is there's much less um, fathering to do now, Don is largely self-sufficient.	602-603 We're looking at a journey, and there has been progress. If I remember how she was when she was in primary..	83-85 So when she was younger she could be totally irrational, there was no way you could actually deal with it, but nowadays I feel I can, so I think that side of my, of the role, has, has increased.
<i>You know the difference between men and women?</i>	182-183 She's sort of become a housewife, and, she would take him to school	x	82-83 Cos I'm a man and I can say things like that, I can get away with it, she couldn't. 103-104 You know the difference between men and women, you know that we all take, we take a different view.	13-14 I am the, um, the main carer at home, my wife works full time, and I've done that since um, Samantha and Janet were very young obviously.	33-34 Before we got married, after, gave up work after the children were born. 502-503 Mothers are in need of help, because they're stuck at home with the kid.	348-349 I was really glad that my wife was doing what she was doing, because I couldn't do it. 271-272 I'm thinking as a father I've got to bring this person on, and, and give her the skills.	61-62 I'm fortunate in that when she goes off the rails a bit, it's nearly always my wife, that, that takes that,

The importance of knowledge & understanding	1 Peter	2 Ben	3 Sam	4 Henry	5 Andrew	6 Charles	7 Mike
Typically different	185 He was different, and he knew he was different. 121 Came out with A*s on everything.	513-514 He's looking terrible, you know, he used to, he's he can look quite good, he can be quite good looking.	138-139 Mark has got a very quirky attitude to life, as you know from Asperger's. Uh, and it can be hilarious, can still be crotchety at times. 561 Yes he's different, delightfully different, some of us think	366-367 She's trying to do things in the right way, but just not at the right time and not in the right order.	308-309 Don is now an adult, um, generally a fairly responsible adult, um, so I try to treat him as a person.	53-55 You'd be, in common with most of the rest of the world, you'd say that's a lovely young woman, competent, articulate, intelligent, what's the problem, you know, what's the problem?	365-366 The greatest things about Angela is that she doesn't give up. She's a real tryer, as evidenced by all the qualifications she's got. She's far more qualified than many.
Diagnosis: a road map or a bereavement?	930 We didn't access because we didn't know, the full, the diagnosis early enough.	115-117 Things got difficult, sort of when he was 15, but we had no diagnosis, and we didn't realise how difficult.	43-45 And she said yes, it's Asperger's. And of course from there on, I don't say it became easy, but it became easier, in as much as we'd got a road map, and we could see what had to be done.	123-125 It changed when she had her diagnosis. Um, sometimes I look at you know, these pictures, before she was, and I think, is that the same person?	x	128-129 The diagnosis helped her. Suddenly she was, she was, freed of, of self-doubt, she understood. 123-124 I'd possibly describe it as the worst thing that's happened to me in my life so far. It was, it was like a bereavement.	246-248 So we kept from her, in a way, the fact that she was different to the point where, there was something that could name her difference, which could make her feel second class.
Just having that knowledge makes a big difference.	552-553 We knew there was something odd going on, when he was, and, my wife had been reading up. 678-679 And she gets on alright with Simon, can cope with him, she understands.	129-130 We didn't know what the matter was. Nobody told us there was a problem, but there was clearly a problem. With the benefit of hindsight. 664-665 She was so naïve and she just didn't even have the first inkling of how to engage.	32-34 Maria knew from the start there was a problem, but didn't know what the problem was. 242-243 Another lady, who does seem to have taken it on, and she read all the notes etc etc and understands it all pretty well.	331-332 So I think it's learning to live with that. Learning to rethink things. Learning to um, change your expectations. 707- 709 She was very good at um, she understood Janet's problems, she had a knowledge of spectrum disorders, she could communicate that to the school. 774-776 Just having that knowledge makes a big difference.	slower. 101-102 And also a lot of people misunderstand that he, quite a lot of times people have misunderstood what he's doing and turned nasty. 274-275 Usually it's been daughters of friends, of people and church, who'd, who know about Don.	180-181 That was the start of my recovery, because I, that guy helped to, to, helped me to understand why I was thinking the way I was thinking. 320-321 But once those different rules, that different way of thinking was in place, um, it just, it made life just a bit easier.	226-227 I mean I think I'd known it, but nothing had actually been said. 301-302 We're literate, we've got quite a lot of books on the subject, so we can read, and I go to conferences x

The emotional impact	1 Peter	2 Ben	3 Sam	4 Henry	5 Andrew	6 Charles	7 Mike
<i>Seeing my child suffer was testing and it was painful</i>	261-262 We've had times where he's been literally screaming and banging his head	860-862 I'd love him to get over this, and I don't care what he does, but do something, and do something that he enjoyed. I just, I have the same hope that I would have for any child.	275-277 I'm going to sit here until you want to come and talk to me properly, until you're ready to re-join the family, otherwise we'll stay here all night. But I just sat there. Um, and, that was testing, um, and it was painful.	108-110 And I find it frustrating, cos I actually think that her, if she can overcome some of those things her, her journey would be much more sort of straightforward. Cos you can't avoid stresses in life.	426-427 Also children tormenting Don because he's different. Stealing his..	30-31 Which is really quite distressing when your child starts to do stuff like that.	416-417 It's difficult to make her happy, very easy to make her unhappy.
<i>The ability to provoke that intense emotion.</i>	768-769 I love him dearly, but I find him ever so frustrating. He drives me absolutely mad.	319-320 That's when I really panicked, I thought he was into uh, coma or something.	578-579 There is an overlaying sadness there which is potentially worry, very worrying indeed.	487 There's the ability to provoke that intense emotion. 479-480 It was awful. And I never ever thought I would be like that, I never thought I had that in me.	317-318 Sometimes I just ended up by having to sh, by shouting at him, when he wouldn't listen.	141-142 I think I was depressed, now. I think I can understand, and my wife I think, certainly understood that I was depressed.	322 How she would cope without us, that's a significant worry.
<i>Getting away from all the issues at home</i>	392-393 This place is my get out clause, I wouldn't be able to be at home with him all the time.	402-404 Well were absolutely shattered, and we went off for a week on holiday, we just, just said didn't care where we went, what it cost, we were just going, don't care, just out of here.	405-406 Yes of course life would have been different, but it, you know, it's not worth thinking about.	414-416 When you're there and dealing with things, and this is what I've found in the past as well, um, you can sort of cope a little bit better. But when you're home and thinking about things that it's harder.	315-316 It has been quite, uh, stressful at times, um, and that's bound to affect how we react.	144-145 And the way that I dealt with that, probably in common with most men, was by, by separating myself from the problem.	x
<i>Those other events have shaped quite a lot that has happened</i>	109-110 In a way he's been through quite a traumatic life, um, so uh, you know one thing and another. 263-264 Nowadays he just gets into a real deep depression and goes off and we'll hardly see him for a couple of days.	46-48 She is uh a bit stuffed, she's living alone in a house, with not much in the way of cash, and uh, so she's a bit of a problem for us. Umm, my wife's mother died in May. 459-461 I've come round to recognising now that it's a sickness	72-73 I've been coloured the whole time by Simon's problems almost more than Mark's really. Mark's problems are nothing compared with Simon's.	60-61 In a way all of those events have shaped quite a lot that has happened 267-268 Because of what she did before, it opens up a lot of feelings for us as well, you know.	x	214-215 I mean other personal, my father just died in October as well, so um, what, when we thought we were going to be, have a little more time to ourselves, suddenly we're into this probate situation.	x 389-390 So the worry, the big worry is that that (anxiety) tips over into depression. And it. So I work really hard, that's why I work really hard on it when she gets like that.

The importance of good support.	1 Peter	2 Ben	3 Sam	4 Henry	5 Andrew	6 Charles	7 Mike
Perpetually badgering for support	896- 897 Fortunately one day, we managed to get a Dr, one of the doctors in a good mood, and um, they referred us to the child and family clinic.	250-252 Over the last few years I've tried, just bent over backwards to try and get him help to try and find him pathways and all the rest.	436-438 Someone said, no, no, he shouldn't be statemented, and that's what the pink file is all about. The arguments that went on over the months with the council etc. etc.	727-728 They never picked up on those things. And it was only cos we were quite pushy I suppose, and said, look she needs to be seen by a psychiatric doctor.	447-448 There was a number of times when we called people cos they were throwing stones at the house.	96-97 We were perpetually badgering the school. Finding out, how's this going, what's happening, why's she not getting support, what's going on?	311-314 Never sought, uh, support for ourselves, for the family as a whole, 48-49 We didn't force it through, we didn't follow it through hard enough, um, to get her diagnosed at a younger age.
With support life can flourish, but we've had nothing	905- 906 The junior infant school, um, couldn't cope with him, didn't know what to do with him. 927-928 Cos he had support sometimes, he could cope with the times he didn't have support. 789 Get a bit upset sometimes, when, cos he doesn't have the interests that I have. 1139- 1140 Me and my wife get on very well together, we've been married a long time now.	355 No one comes, no-one, nothing, we've had nothing, we've had nothing. 186-188 The school were incredibly helpful, they were just bent over backwards to try, try and uh work this through. 69-70 Our relationship's got a lot better, recently. At least we've resigned ourselves to make it so.	163-165 And they've been absolutely useless, um completely and utterly useless, until now, and, mainly because no-one ever stayed on the case long enough. 187-188 He does it, and it's been very important, so Employability get a couple of plus points. 111-113 I don't want to imply that, that we were rifted, cos we weren't and we used to sit, sit in the dark at night and say well, and I'd say this to her, I couldn't get through this without you.	453-454 The school hadn't contacted me or anything, they did, they did actually do it really badly, which they realised afterwards. 695- 697 CAMHS were excellent, her, her nurse, she had um, a paediatric psychiatric nurse, who was excellent, um who stayed with her longer than she probably should,. 532-533 Probably in some ways I think I've almost become too reliant on her. 535 We are quite supportive of each other.	391-392 The supposed support services for helping children get jobs after school, ..., totally ineffective as far as I can see. They, they, talked but they didn't get anything. 383-384 The schools have been extremely good, um, impressively good. Um, and, they the've gone out of their way to help. 318-319 Kate doesn't like that, still didn't think I ought to shout at him. Um, and, we've um, disagreed on how we ought to deal with him	98-99 Lots of really good sounds coming out, but the delivery was poor. Didn't happen, didn't work. 112 With support her academic stuff is, life can flourish. 186-188 We saw a family relationship therapist at CAMH, it was the most, life transforming experience I think I've had. And I, I, wonder what I would have done without that actually. 159-160 Whereas when I tried to interact with my daughter, there was tension, there were tensions there.	197-198 We're parents who have no experience of this sort of thing, um, he was just so wrong. 268-270 We have very good access to social services. There's one person who's been there the whole time for her. Um, so I would say we're lucky in our borough. 98-99 It's the family that is affected, and I'm part of the family, cos we're a close family, so it's the way we all deal with Angela that matters.
Maintenance or collapse of exterior world	653- 654 Other than family, we really don't have any social contact with anybody.	584-588 (do you think it's impacted on your relationship with other members of your family?) Nope (No, umm, and with friends?) Nope, I wouldn't say so.	417-418 I'm very content with the friends I've got and we have a great time, and they're very understanding.	968-969 Not the only dad in the playground, but socially when you're at home, more, being a dad, it is harder. 326-328 Lots of people were very supportive, some people were, some my friends weren't supportive.	247-249 When Don was a child it was very difficult to entertain, so, um, social life was reduced and we couldn't really invite people round because Don's behaviour would, um, spoil it.	403-405 You know, I would say my exterior world kind of collapsed. It, the, the, the compass came in, the boundaries came in. I was, I was no longer operating in, in as large an orbit.	152-153 People are always very sympathetic, um always very. Angela's lovely , I mean, everyone that meets her, she brightens up their lives.

APPENDIX O. Extract from Reflective notes.

Reflective notes around an interview (identifying details removed or changed)

Before interview:

- Something about the tone of email interactions made me unsure of father's commitment/ interest in taking part in interview. I felt some anxiety about this, I think this was around a worry that we might complete the interview etc, and then the father might withdraw. I gave several opportunities for him to withdraw at this point instead.
- Some phrasing and comments in emails also made me wonder if this father might have ASC traits himself. I reviewed my interview schedule and thought through previous interviews to plan for any challenges this might present to the interview.

Impressions of the father immediately after interview:

- I felt that the father was quite anxious about the interview and was anxious to make me welcome and to be useful for the research.
- He was quite self-deprecating, possibly linked to the anxiety. I felt more of a need to reassure and make very visible signs of listening and agreement than with other interviews.
- He was very anxious about his adult child over-hearing the interview. This made me wonder about what is said and not said in the family, and if there are secrets kept from the child.

Impressions of the account of experiences:

- I felt that there was a lot of focus on the impact of things on self rather than child. Other interviews have tended to start with own experiences, then start talking about how things might be for their adult child. This father stuck more directly to the questions asked, in relation to own experiences.
- Some tendencies to go off track in talking about own interests. This, and other elements of our interaction added to my impression that this father had traits of autism. This did not present any difficulties to the interview.
- I found myself feeling somewhat sorry for the adult child at times in listening to the interview. I had the impression that the father preferred their other child. Some things that the father said jarred with my views of things, such as accounts of being too embarrassed by adult child to do some things. The father's comments made me feel somewhat angry with him. I think that this anger was around a bigger feeling that the father viewed his son in a negative manner. Thinking through the entire interview though, these negative feelings seem a part of his experience, but he also talks positively about his

son at a number of points. The negativity seems directed at the behaviour, and he also seems to be thinking about how his friends might respond to challenging behaviour, so he could be seen to be protecting both his son and his friends. I will need to consider this balance when analysing the transcript, as it would be easy to be drawn into either the negatives or the positives, and lose the bigger picture of a more varied experience.

Addition whilst transcribing:

This sense of embarrassment over his younger son was apparent to me again. He makes a lot of comparisons to his elder son, who seems somewhat idealised. Seems to be some reflection of how (father) feels his gets on and can communicate with each of his sons.